

### Care home stories: aging, disability, and long-term residential care

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SALLY CHIVERS,  
ULLA KRIEBERNEGG (EDS.)

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# CARE HOME STORIES

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AGING, DISABILITY, AND LONG-TERM  
RESIDENTIAL CARE



Sally Chivers, Ulla Kriebnerneegg (eds.)  
Care Home Stories

The series **Aging Studies** is edited by Heike Hartung, Ulla Kriebnernegg and Roberta Maierhofer.

SALLY CHIVERS, ULLA KRIEBERNEGG (EDS.)

## **Care Home Stories**

**Aging, Disability, and Long-Term Residential Care**

**[transcript]**

The printing of this book was supported by the Trent Centre for Aging & Society, Re-imagining Long-Term Residential Care: An International Study of Promising Practices (PI: Pat Armstrong file 435-2015-1787).

KARL-FRANZENS-UNIVERSITÄT GRAZ  
UNIVERSITY OF GRAZ



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## Acknowledgements

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This book comes out of a collaborative friendship that emerged through mutual interests in how the humanities could re-think old age, especially its stigmatizing association with nursing homes. On separate continents, we had been reading and writing about the same novels and films with similar goals in mind. Coming together to ask questions about what stories offer to re-thinking the institutionalization of late life has led to scholarly fulfilment and personal joy. So, we start by thanking each other.

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Rhonda graces the cover of the book thanks to the generosity of Nelson McDonald, who granted permission without cost to use Holly Crooks's image of Marguerite McNeil in the title role of the short film *Rhonda's Party*.

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For moral support, we are so fortunate to have our families, especially Doug, Sepp, and Lena. We thank them from the bottom of very full hearts.

# Prologue



Betsy Struthers

## THE PUSH

*Such a beautiful day*, Mom welcomes me in. She's fully dressed, hair freshly permed. *Can we go out for a walk?* In the elevator and along the hall to the vestibule, she chatters about the blue eggs in the nest on the dining room window sill. When they will hatch. When the chicks will fly. The whole floor's making bets. *Smell the lilacs, listen to those birds!* We head for the glasshouse in the park, three blocks, one busy street, and there we're stopped – I can't tip the wheelchair over the stubborn curb, afraid I'll lose my grip. *Let me*, two tattooed arms crook down to lift the chair and Mom, as if they were weightless, and sets them right. *Thanks*, I stutter. He waves my words away and bows, *Grandmother, I honour your days*, turns and shambles off to join a group of men sprawled, playing cards on a low stone wall. She's quiet when we enter the tropic dome, the rooms of tulips, hyacinths, the crown of thorns. *I'm tired, take me back*. Click of tires over pavement cracks, the rhythm like that of my son in his stroller, the same strain to push against the pull of the slope ahead. The signal flashes red. I stoop to tuck her shawl. *You're good to me*, she says and clasps my hand in both of hers. Like that, we're stuck, waiting for the changing of the light.





# Introduction



# Care Home Stories

## Aging, Disability, and Long-Term Residential Care

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*Sally Chivers and Ulla Kriebelnegg*

This book is motivated by the need, in the face of population aging, to tell new and better stories about institutional care. We take a close look at the stories that circulate both in the popular press and across forms of more imaginative popular culture in order to understand social, cultural, and political messages that attach to what are commonly called “nursing homes.” We gather stories from people who have worked and lived in long-term residential care that capture the rich interplay of subjectivities and the complex relationships that emerge in those spaces, both of which depend heavily on context.

Whether in a nursing home, care home, retirement home, assisted living, or other form, institutional care for seniors offers a cultural repository for fears and hopes about an aging population. While people adamantly desire to age well at home, without making the big move<sup>1</sup> to render their latter years more manageable, and policy makers play to that desire, apparently buoyed by how it offers them an opportunity to download the costs of care onto the family unit, the fact remains that many contemporary senior citizens will require institutional care, and some might even choose it. Enormous changes have occurred in how institutional care is structured, adapting models from the poor house through the hospital to the home and the hotel and the village. But the legacies of the poor house and the hospital persist, creating panicked views of the nursing home as a dreaded fate for people who may actually benefit from new living quarters in late life. The paradoxical nature of a space meant to be both hospital and home offers up critical tensions for examination by age/ing studies scholars. In this book, we gather imaginative critical and personal essays that challenge stereotypes of institutional care for older adults, that illustrate the

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1 | Famous gerontologists Anne M. Wyatt-Brown, Helen Q. Kivnick, Ruth Ray Karpen, and Margaret Morganroth Gullette reflect on the transition into a Continuing Care Retirement Community in *The Big Move: Life Between the Turning Points*, Indiana UP, 2016.

changes that have occurred over time, and that illuminate the continuities in the stories we tell about nursing homes.

We want to change the script, in part, for Rhonda, the fictional character depicted on our book cover. The short Canadian film “Rhonda’s Party” portrays the collision of the unexpected with the predictable in the life of what we are calling in this book a “care home.”<sup>2</sup> Rhonda doggedly prepares for her friend and fellow resident’s 100th birthday party while, unbeknownst to her, staff are signing papers that verify that her friend has died. The film lingers over choices about whether to continue with the party ritual to cover up the markedly bureaucratic form-signing rituals that punctuate death in the long-term care environment. Those contrasts are mirrored by visual contrasts in the cover image, between Rhonda’s serious face and the celebratory joy implied by the balloons, between the colourful round curve of the party balloons and the rigid dark lines of the corridor. Such potentially generative tensions permeate our book, which uncovers many ways in which the enforced rigidity of care home spaces is challenged by an undeniable infusion of humanity. Most importantly, Rhonda’s firm gaze at the camera reflects the centrality of the human experience, in all its variety, in our thinking about care home stories. Our humanities perspective enriches a domain too often dominated by purported economic exigencies.

The need to tell and analyze care home stories intensifies due to this era of New Public Management in which care homes currently operate. For example, immediately upon entering a “care centre” in the Canadian province of Ontario, visitors encounter a “Strategy Map.” This sign is the very first thing people see in what is advertised as a *homelike* atmosphere. Using corporatized language, this “map” explains how “Know How” leads to “Internal Processes” that benefit the “Customer” leading to “Financial” gains. These elements are pictured as all working together towards “strategic goals” of being *bigger* than other “retirement lodges” and the conglomerate that owns the care centre becoming the #1 choice in Long Term Care the following year. The map flows into a final coloured box which articulates a “Big Hairy Audacious Goal”: “to become the

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**2 |** The nomenclature of “care homes” is thorny enough to merit its own chapter. While “nursing home” is commonly used in North American popular contexts, it means different things in different jurisdictions. Not all the spaces we explore in this book include nursing, though all have to do with some form of paid or unpaid care work. While we don’t ignore the institutional legacy of these residences, we don’t want to unduly focus on that aspect of long-term residential care, itself an unwieldy phrase that conjures up unpleasant associations for some constituents (for example, indigenous people in Canada who were forced into residential schools). We have chosen to think about care home spaces and care home as a term, for all it evokes, in this book, though the other terms show up in relevant contexts.

Company that most changes the image of seniors' services from a necessity to a desire by 2020."

On a personal visit to that care home, when Sally chatted with another visitor, that older woman openly gestured to and scoffed at the sign, asking, "What does *that* have to do with me?" That question has stuck with us as we have gathered personal and scholarly reflections about Care Home Stories. The chart regretfully has everything to do with the older woman visitor because it reflects the values of the institution where she has had to choose to place her husband – this is a relatively fancy non-profit institution, not a last resort among last resorts. The people who work there are forced to appear to think in terms of the large boxes – "know-how," "internal processes," "customer," and "financial" – so that their employer can grow. Added to which, they work, and he lives, in the most highly regulated yet worst funded sector in Ontario, causing them to do more charting than body work.

The "Strategy Map" tells that story and not myriad others that the visitor might desire and immediately be able to place herself in. This book seeks to contextualize that currently dominant story of long-term residential care: the one that appears on the surface to have nothing to do with the people who live there and the people who love them. We put that version among other stories of everyday life in and around care homes. We want to know as much about Rhonda's party preparations, her anticipation of a friend's remarkable centenarian celebration, and her imminent grief as we do about the hospital-like corridor setting, the imposing nursing station, and the bureaucratic mechanisms that manage death in the care home where she lives.

We have gathered the stories and studies in this book because we believe that we do indeed need to be audacious in setting goals for changing long term residential care. But different contexts need different goals, and so we should not narrow ourselves to one Big Hairy Audacious Goal. We need to think about what values underlie the systems in which long-term residential care operates, beyond those that situate seniors in need of care as "customers" who contribute to or sap "financial" viability. Instead of aiming to grow our business to become number one, and instead of supporting the notion that public institutions ought to be run like businesses, we should all work together to think about many different ways in which long-term residential care in late life could become something desirable rather than necessary.

## WHY CARE?

While thinking about care might seem to limit what we imagine later life to be, the question especially of long-term care propels social and cultural meanings of population aging. When the popular press is overwhelmed by negative

images of older people, it is not just evoking fear about what each person's fate might be – a deep fear of physical change that could bring pain and restriction to the activities of daily living, not to mention raising the spectre of death. Beyond that, images of older adults overtaking youth – often pictured as a giant wave – are about dependency. The idea that younger generations will have to do the work of care and, worse yet, pay for care is a significant portion of what makes such demographic projections play apocalyptically. Thus, we focus on care here because it is at the crux of age/ing studies. Changing the meaning of care stands to substantially change what it means to “age well.”

## WHY HOME?

Home appears throughout understandings of long-term residential care as an unquestioned ideal. The notion that institutional settings are improved when they are homelike goes virtually unquestioned. Not only is that assumption worth up-ending, so too must we question whose home these spaces are meant to be “like.” As Annmarie Adams and Sally Chivers point out in the context of design, “how to capture and conjure up an image of home to residents of various backgrounds” poses a “perennial challenge” (138). It is, perhaps, easier to pinpoint what is *not* homelike than to effectively describe let alone manifest homelikeness. We focus on home here because it is held up as an unquestioned good, particularly in policy documents that stress the widespread desire of people to age in place, meaning in their homes. But home is a thorny concept that benefits from interdisciplinary and international scrutiny.

## WHY STORIES?

In *The Truth about Stories*, Thomas King famously states, “The truth about stories is, that’s all we are” (2). Yet care homes are not usually thought of as sites for *new* stories – instead the people who live within them are thought to be vessels for stories of a past from before they made the “big move.” We turn to stories to put the key terms of “care” and “home” together because they offer a meaningful and aesthetic way to contain and revel in multiplicities. A story can offer a few vantage points without taking a side but a story can also effectively and convincingly play favorites. There is no need for objectivity but rather a helpful indulgence in productive subjectivities. We think there are new stories to tell regarding care home spaces about, with and by the people who work, live and visit them.

## THE CONTRIBUTIONS

The 16 chapters collected in this volume, together with five poems, each in its own way, challenge dominant understandings of institutional care, thinking through how it has changed, and elucidating what has stayed constant in Care Home Stories. They seek to answer questions such as, how do stories about care homes challenge existing or create metaphors for institutional care? What stories do people living or working in care tell? Who tells care home stories, and who doesn't get the chance to? How do people think they know what care home life is like? How are care homes represented in poetry, film, art, fiction, and popular media? And how do these stories change views about institutional care?

The book consists of four main sections with four chapters each: "Personal Perspectives," "Working and Playing in the Care Home," "Literary and Cultural Perspectives," and "Social and Historical Perspectives." Additionally, Betsy Struthers's poetry about her own mother's dementia and death in a care home helps structure this volume: each section is preceded by one of the five poems she kindly agreed to share with us. "The Push" is our prologue because it beautifully connects a very specific moment in time, a woman visiting her mother in the care home and taking her for a walk in her wheelchair, to our constantly changing roles and positions throughout the life course. More importantly, it emphasizes the importance of intergenerational connections and care at every moment throughout our lives.

The book's first section, "Personal Perspectives," comprises subjective experiences with institutional life. It is preceded by the poem "Pretty Little Angels," which offers a very personal account of a difficult visit in a care home. By describing the unpleasant hospital-like atmosphere of the facility with its elevators and nurses, its pastel colors, plastic vases, and disinfectant smell, the speaker conveys the uneasy feeling entering such a surrogate home entails. The ironic twist at the end of the poem almost offers some comic relief, but it still hints at the difficulties and ambivalent feelings that accompanying one's parent through the last stages of their lives may bring about. In the opening chapter that follows, almost weekly triangular care-home visits between 2008 and 2011 with her mother, her mother-in-law, and her good friend Robert Kroetsch are at the center of Aritha van Herk's creative non-fiction meditation "At Home or Nowhere: In Memoriam – Pat Sharp in Edmonton; Marretje van Herk in Edmonton; Robert Kroetsch in Leduc." She offers "a personal exploration from the perspective of a family member and friend who watches and engages the 'care home' from without," as she describes it in one of her initial email conversations with us (van Herk). She not only offers an account of her relationships with these three aging and increasingly frail persons but also shares, in her very own poetic voice, her reflections on how these "explorations into the heart

of oldness” shaped her own ideas, fears, and imaginations of growing old. In the next chapter, “Home Interrupted,” Monique Lanoix examines how institutional care offered to younger individuals makes it difficult to feel at home in an institutional setting. She tells the story of her husband’s institutionalization in a Québécois care home upon a severe accident that left him severely injured and in need of long-term care. Lanoix draws out her experience of the institution’s liminality and transience, analyzing how in addition to the spatial setting, daily practices of care continually emphasize the “not-home” within the living environment, creating what she calls “two-home syndrome.” She argues that homelikeness cannot be produced and maintained by the physical environment alone, but should be inscribed in the practices of care. This interest in possibilities for improvement also characterizes Amanda Barusch’s chapter, “A Place for Dad: One Family’s Experience of For-Profit Care,” in which she reflects incisively on the challenges she had to face when her father, who lived many hours away from her with his second wife, was diagnosed with dementia and needed care that his wife could no longer provide herself. Barusch, an academic gerontologist, documents the process of gradually moving her father into institutional care with sensitivity, including personal e-mail conversations with Catherine, which underline the challenging role Barusch found herself playing. Barusch contextualizes her personal story with a very informative overview of the development of long-term care in the United States. In the final chapter of the section, one of the rare first-hand accounts of what it is like to reside in a Continuing Care Retirement Community is provided by Anne Wyatt-Brown in her essay “Life in a Continuing Care Retirement Community: On Not Being Invisible.” After outlining why she eventually decided to move to Roland Park Place, she addresses the challenges this transition has brought about for her by juxtaposing her own experience as a gerontologist with self-help books, such as Stephen Golant’s, on where to live in old age. She reflects on her struggle to keep her autonomy and independence by reporting about how she and her fellow residents, who had become her friends, reacted to the change of staff in the Roland Park Place’s fitness center, a place of crucial importance to her as it had given her a sense of belonging. She argues for the need to combine gerontological knowledge with personal observations in order to help others make good decisions on where to live in old age.

Section two, “Working and Playing in the Care Home,” is prefaced by Betsy Struthers’s poem “Second Sitting,”<sup>3</sup> which contemplates the lack of personal attachment and friendship in a care home and emphasizes the anonymity shared by its residents. The four contributions that follow center on personal experiences and on-site research that has been conducted in care homes, albeit

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**3** | An earlier version of “Second Sitting” was previously published in *Sugar Mule* 33 and is reprinted here with permission.



from very different perspectives. In “Shelter in Place,” Laura Dunbar shares a perceptive and poignant personal story about how she got to be a nurse, how she started work at a nursing home in Ontario, and how she struggled with reconciling her daily duties in a highly regulated institution with her sense of what adequate professional and personal caregiving meant for her. With her piece, she lends a voice to the many nurses and nurses’ aides in care homes who are usually underrepresented in research despite the fact that the quality of care largely depends on them as they try on a daily basis despite adverse conditions to help their clients maintain their dignity, and to treat them with kindness and as human beings. The centrality of caring, personal relationships at all stages throughout the life course is also at the centre of Peter Whitehouse’s article, “Long-Term Care for the Future: Just What is Real Anyway?,” which offers two stories about what he calls the realities and unrealities of care. His account is based on the one hand on his experience of living as a part time resident/researcher in The Terraces, an independent/assisted living facility that is part of Baycrest Geriatric Centre, Toronto. On the other hand, it tells about Whitehouse’s visit to Hogewey, a long-term residence in The Netherlands for people with dementia. Sharing the story of what has shaped his view on dementia care and drawing conclusions from his on-site research, he argues for a change in our understanding of long-term care that focuses on intergenerational learning in order to create resilient communities that can face the social, economic, and ecological challenges ahead of us. New perspectives on dementia care are also offered by Julia Gray, Pia Kontos, Sherry Dupuis, Gail Mitchell, and Christine Jonas-Simpson in their co-authored chapter “Dementia (Re)Performed: Interrogating Tensions between Relational Engagement and Regulatory Policies in Care Homes through Theatre,” which aims at disrupting the tragedy discourse that informs cultural representation as well as policy making. Presenting two scenes from their research-informed play *Cracked: New Light on Dementia*, they show how theatre productions can intellectually *and* emotionally engage audiences. *Cracked* was developed to open up a playful, social space to raise questions about current conceptions of dementia, expose unjust care practices and policies, and facilitate envisioning and inspiring an alternative care culture. Their analysis is framed by the personal/professional experiences and research that informed the scenes’ development, as well as post-performance evaluation data where dementia care practitioners discuss specific scenes as catalysts for change. Similarly, Aynsley Moorhouse discusses how theatre can facilitate new approaches to long-term care: In “‘Hooray for You and Me’: The Story of a Theatre Group,” she illustrates how she developed and implemented a five-month theatre and digital storytelling group for residents of a care home in Toronto, Canada. She adapted an online blog for the chapter, guiding readers through the development process and sharing her personal observations on

how the production took shape. Her blog thus became a relationship-centred document that tells a care home story full of joy, laughter, creativity and growth.

Betsy Struthers's poem "My Mother Defines Purgatory," opens section three, "Literary and Cultural Perspectives." The poem offers a limited inside point-of-view of an old woman waking up slightly confused in her care home bed. She is helpless, disoriented, and desperate, also because the care she receives lacks compassion and does not fulfill her need for affection and kindness. On the contrary, she feels humiliated. The poem, like many fictional texts set in care homes, also criticizes the lack of privacy in institutional settings and, in a nutshell, describes what is commonly understood as "the nursing home specter." While some works of fiction centre on the lack of agency, however, others portray old people as "active agers." In her chapter, "The Third Age in the Third World: Outsourcing and Outrunning Old Age in *The Best Exotic Marigold Hotel*," Amanda Ciafone turns to cinematic portrayals of old age as a time of affluence, self-determination, and activity. She explores old age through a critical reading of post-colonial theory and discusses India as the setting of these stories. Her text centres on the argument that the country is coded as exotically 'other' in order to portray the old characters as living the ends of their lives fully: they meet new lovers, build familial networks, and find new professions and passions. These life developments in old age are made to seem exceptional, then, and dependent on a fantasy backdrop to play out. A more realistic background is presented in Peter Simonsen's chapter that investigates how, in Ian McEwan's novel *Saturday* (2005), risks of terrorism and dementia are curiously parallel. It is typically read as a novel about the everyday fears and constant worries that entered many individual's lives in the aftermath of the terrorist attacks of 9/11. This has shielded us, Peter argues, from an equally important aspect of the book: the way in which it captures the growing fears and constant worries entering many of our lives that we will end up as dementia patients. Patricia Life in her chapter "Outside the Nursing-Home Narrative: Race and Gender Exclusions in *Green Grass, Running Water*" then considers what types of texts are missing from what she calls the nursing-home-narrative genre and what types of people are absent from nursing homes. People such as the four old Indigenous patients who run away from the care home in Thomas King's *Green Grass, Running Water* are excluded, feel excluded and/or exclude themselves from residency in Canadian institutions. Life's study of King's text reveals a need for age theorists and governments to address the thorny issue of intentional and unintentional segregation of care according to race and gender. Katrin Berndt and Jennifer Henke explore in their co-authored chapter "Love, Age, and Loyalty in Alice Munro's 'The Bear Came over the Mountain' and Sarah Polley's *Away from Her*" how the short story and its film adaptation deal with questions of commitment in a lifelong marriage challenged by the effects of dementia and the female protagonist's move into a care home. They approach

both works from a narratological perspective and investigate how both fictional representations of love, loyalty, age, and dementia invite a reading that emphasizes a new beginning even at a late point in life.

“Rising Fog,” Betsy Struthers’s poem about saying good-bye to a mother left behind in an unpleasant care home, initiates the fourth and last section of the collection, “Social and Historical Perspectives.” This last poem finishes a kind of narrative arc from ambulatory to bedridden, and starts by quoting Emily Dickinson’s famous last words: “I must go in; the fog is rising.” The lyric I, a daughter who is sitting on a bus on the highway, returning home from a visit with her frail mother, finds herself haunted by the vision of her mother’s clenched fists and stare when she has to leave her behind. She tries hard to concentrate on what she sees outside: an owl, crows, geese, the lake, and rising fog: over the lake, the moraine, and from her own breath on the bus’s window pane. The fear of an old age defined by decline, dependency, and the loss of agency that Betsy Struthers expresses through her poetic voice is addressed from the perspective of sociology by Chris Gilleard and Paul Higgs. In their chapter, “An Enveloping Shadow? The Role of the Nursing Home in the Social Imaginary of the Fourth Age” they argue that the nursing home is both a site and a symbol that fashions the social imaginary of a fourth age as it plays a pivotal role in articulating the fourth age, the practices that play out under its shadow, and the contradictions caught up in its denial. In the next chapter, Marija Geiger Zeman, Zdenko Zeman, and Mirela Holy present a sociological reading of a Croatian novel in their analysis “A New Home, A New Beginning, A New Identity: Old Age, Life Narrative and Self-Presentation in the Novel *The Real Captain’s Sea* by Zvonko Todorovski.” It focuses on literary presentations of institutions of older persons, gender roles, and images, by which, finally, the questions of identity, and dramaturgic, relational, emotional, and ontological aspects of life narrative come into play. In the following chapter, spaces and places of care are at the centre of Isabel Atzl and Anamaria Depner’s text “Home Care Home: Reflections on the Differentiation of Space in Living and Care Settings.” Using an inductive approach, they analyze from an interdisciplinary perspective the role of objects in past and present nursing and care settings. They discuss how nineteenth century nursing textbooks describe how patient rooms should be designed and set up to be in line with the medical guidelines of the time and compare them to state-of-the-art textbooks. Also, they include excerpts from a field report to portray an example of daily life in care facilities. Finally, James Struthers’s chapter “Home, Hotel, Hospital, Hospice: Conflicting Images of Long-Term Residential Care in Ontario, Canada” rounds off the collection. He explores a series of recurring stories about care homes that featured prominently in policy discourse and in the media primarily during the post-World War II era in Ontario and traces the

development of caregiving institutions and their discursive framing from the poorhouse to modern-day facilities.

Collectively these chapters and poems show there is much to be said about a place that too often is construed as a failure, a last resort, and a fate worse than death. In the course of working on the book together, we have had countless discussions with other colleagues and friends about their own experiences making decisions for family members with regards to long-term care. We consider this book part of a longer and bigger conversation, and we hope you will join us.

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**Part 1:**  
**Personal Perspectives**



Betsy Struthers

## PRETTY LITTLE ANGELS

Hope the elevator will be slow, or out of service,  
but it pings open the second I touch the button.  
At least it's empty. At least, for the slow ascent  
to the fourth floor, there's time to compose  
what to say. How to say it. Nod to the nurse  
who nods back, smiles – or frowns, can't tell,  
don't stop to ask. Don't want to know. Pass tables  
set with plastic cloths, acrylic vases, lurid  
pink carnations. More pretense. Mom's door  
is closed, a new sign, her scrawl on white paper:  
*Knoc befor Enter*. Letters large at the top, shrink,  
drift to the lower corner. Tap. Wait. Tap again. Push  
the door open, peek in: she's still in the bed, sheet  
tucked under chin, quilt bunched at the foot. That  
smell: disinfectant, floor polish, piss. Hesitate  
to enter, to wake her startled and afraid. Or  
not wake her. Too long a pause until she croaks,  
*Is that you?* Ease in, shrug off purse, jacket,  
it's hot in here. Open curtain, let in light, air.  
The floor a spill of photos, crumpled notes.  
She's been moving things again. Losing things.  
Crying on the phone about lost things. What  
has been taken from her. What she misses  
so much, has willfully abandoned. Clinging  
to memory, she has turned her back  
on the pigeons cooing on the sill, the children's  
singsong in the park across the street. Hears  
only sirens – police, fire, the ambulance  
she waits for, that will come for her. *When  
will it come?* She clutches my wrist. *Where  
is your father? Is he really dead and buried?*  
And when I say *Yes, years now*, she begs,  
*Will he wait for me? All this time in heaven  
with the pretty little angels, won't one get  
her hooks in him before I'm let to go there?*





## At Home or Nowhere

In Memoriam – Pat Sharp in Edmonton; Marretje van Herk  
in Edmonton; Robert Kroetsch in Leduc

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*Aritha van Herk*

During the years between 2008 and 2011, I made a triangular pilgrimage frequently enough that it began to take on the shape of a ritual, at times a curse, sometimes a mantra. The journey was in the nature of a requirement, but it was also a pleasure, a practice, a series of epiphanic conjunctions, and it traced that time of my life in a strangely triangular way.

Every week or two – sometimes more often and sometimes less – I would drive from my home in Calgary’s foothills up the Queen Elizabeth Highway north. I have become an adamant Calgarian, and my journeys to Edmonton were undertaken from a foreigner’s perspective and with an alien’s reluctance. Although I had attended the University of Alberta in Edmonton and found there both ardent love and foundational inspiration for my writing practice, Edmonton itself is a city I am wary of, visitor rather than originary. Calgary is where I feel at home, and Calgary is where I intend to live until I die, whether that event is soon or distant.

My visits to Edmonton were an exploration into the heart of oldness. I do not mean that vague category of the aged combined with euphemisms about “senior,” “golden,” or “latter” years, but another oldness, its frailty and frustration, its dread caducity, which can itself be traced to an older time, the eighteenth-century French *caducité*, from the Latin *caducus*, or “liable to fall.”

Falling identifies the cross-over zone between aging and old, the tipping point between self-sufficiency and danger. Falls are the occasion when the old grow intimate with mortality, for the medical profession attributes to falling morbidity, or conversely, attributes morbidity to falling. The whole metaphor of falling is itself laden with misery: the fall of man, a fall from grace, the fall or autumn of life before the discontents of winter and the inevitable conclusion of death. The connection between this chronic expectation and sin, transgression, lapse or wrongdoing is too obvious, but it speaks to the language and the

presumptions that attend our current attitudes toward the old and our fearful and apprehensive attitudes toward their presence. The discourse of prevention and fear attends our “care” for the aged, to the extent that they are themselves infected by the very fear of falling that we fear for them. In the name of prevention, we reduce the scope of movement for older people and terrify them with the spectre of injury and bone fracture. The resultant “care” that we wield as threat and fret over elder parents and acquaintances becomes its own prognosis, and the fall assumes the magnitude of a curse or prediction as confining as the slowness of the aging body itself. The event of the fall argues for a liminal moment that declares competency, and it marks the transition between independence and the need for extended care. The accident – and how many of us have fallen accidentally, from our childhood onward – then decrees a new limitation for the old. We attribute to the fall infirmity, and in loading so much meaning on the slip, trip or over-balance, we inscribe and confine the elders we should encourage to keep moving. The “taxonomy” of falling and the need for prevention of injury resulting from falling then corral the old behind an invisible fence that adds to their isolation and fearfulness.

My own trips up that relentless highway to Edmonton performed a similar and repeated fall, into the past, into the future, into a hiatus of elder care that seemed separate and isolated from the hustle of my current life, my work, my writing, and my personal passions. The best drives were those my husband and I took together, for we had then three intimate hours to talk, to tell jokes, to share our close experience of this changing genealogy and our history together.

As the years passed, my mother and mother-in-law, both elderly, if never old, exerted different pressures and demands, on me, on other members of family, and on the life that they had left to live. They anticipated falling and yet refused to fall. My father, before he was placed in a care home, did fall, frequently (low blood pressure and diabetic symptoms), which terrified my mother, as she struggled, impossibly, to get him back on his feet. My sister, an implacably practical nurse, told my mother to leave him lying on the floor until he could get up – he was safer there than anywhere else because once he was on the floor he could not fall. But our human impulse is to push people upright, to get them on their feet, as if to reassure ourselves that the fall is both avoidable and erasable. After my father had fallen many times, he was placed in a care home, where he was monitored and provided with a walker, and where he did not again fall until he suffered the fatal stroke that finished his life.

That care home was new, cheerful, and well appointed, with many social events and relatively good food, but my father hated it more passionately than the many other hatreds he had harboured in his life. He sat at his desk in his room and read, wrote notes about his life, and yearned to escape. He was happiest when we took him for a drive out into the country; he seemed to immerse himself into the landscape that he had loved and worked for so many

years of his life, the canola fields stretching yellow and lush, and the green swaths of wheat and oats rippling in the Alberta wind. On movie nights, he went down to the social room and got a box of popcorn, which he took back to his room and ate while he watched the news. He was, to quote Robert Kroetsch writing about his own father, “lonesome for death” (*Completed Field Notes* 7), and death came to him ultimately as a kindness, an escape from his body and his enclosure in that pleasant but imprisoning institution. His was the first death, and although I did not yet know, a prefiguration of my triangular and persistent years of driving to visit my mother-in-law, my mother, and my friend Robert Kroetsch.

My mother was the oldest of this trio but was the most overtly furious, and she made a point of expressing her disappointment with the indignities of aging as vociferously as she had lived. Although my father had died in the care home, she was adamant that she would not, and she continued to live in her own apartment – their own apartment – until just before her death. She went directly from that place to a hospice, refusing medical intervention for her cancerous tumour, and she died very shortly thereafter, at 93. Despite her seething impotence in the face of increasing age and disability (she had macular degeneration and was virtually blind), she was relatively lucky, although she would not have claimed good fortune. She was enraged by age, enraged by time’s passage and her blindness, a woman who devoured books throughout her life and in her last years read the library books delivered to her door with a magnifying glass as large as a cookie sheet. She put her thumb into her cup to gauge the level of the liquid, she checked that the stove burners were off by feeling the positions of the knobs, and she refused to carry a white cane or any marker of her disability. “I am not blind,” she declared, as if the very words would deny her condition.

Her indignation was the culmination of a long life of hard work and incredible privation. Eloquent and acerbic, her humour balanced a toughness that she had learned from multiple displacements. She was twelve when her mother died, a loss she grieved her whole life; powerfully intelligent and curious, she had to leave school to take care of her brothers and sisters; she learned the skills of gardening and cheese-making in the Netherlands under the harshest of conditions; she married my father in the first days after the defeat of the Dutch by the Nazis; she gave birth to two children during an occupation that subjugated and starved the entire population; she welcomed Canadian troops as liberators in 1945; she immigrated to a bewilderingly unfamiliar Canada with three children and my father, without knowing a word of English except potato; she travelled by train from Pier 21 and Halifax to Alberta without knowing where or how far Alberta was; she lived in a granary and worked with my father for \$60 a month; she had three more Canadian children; she taught herself to read and write English from my siblings’ elementary schoolbooks; and she worked every day of her life to keep her family clean and fed. She poured into

our brains and our bloodstreams one word and one desire: education. “Study all you can, and you will always have something to fall back on.” Her fierce pride and rage are my inheritance; when I see or experience injustice, I feel the white-hot incandescence of her intense fury at the stupidity and oblivion of people who have lived a life spoiled and indifferent, especially if they are cowards or unconcerned with the pain they cause others.

Visiting my mother meant I had to meet and respect her long-simmering anger, listen to her stories, and talk to her across the chasm separating our experiences, our different lives, my life as a writer and professor a virtual daydream to her.

And I would ask again, “Mom, wouldn’t you be safer and more comfortable in a home?”

“No.” Said with a fierceness that was as decisive and absolute as a boulder of granite.

“But you’d have company.”

“I don’t want company. Why would I want to talk to a bunch of old people?”

“You’d get your meals, and they’d make sure you took your medication.”

“I can cook. I know how to take my medication.”

The circular logic of my mother was more than stubborn; it was irrefutable. She was difficult and demanding and definite, and she loved to argue with me, about every possible subject and position. Argument made her feel alive, and language was a country where she left behind the various infirmities of her body and her age and became all eloquence, as potently expressive as she had been throughout her life, despite her shift from her mother tongue to English, despite her limited formal education. Her refusal of a care home was certainly traceable back to her profound sense of independence, nurtured by a lifetime of certainty that she had to be self-reliant, that nothing and no one would rescue her or come to her defense. Her uniqueness was bolstered by her self-reliance, and that same self-reliance would have been compromised by a care home, even if she might have dared to enjoy the luxury of being waited on. And in retrospective gratitude, I secretly know she would have turned the place upside-down, bedeviling staff and residents alike. My mother had that capacity for chaos, side by side with a sturdy pragmatism. It was the same prescient realism that made her say, as I was leaving the hospice one evening, “Goodbye, Aritha.” She was telling me that she would not see me again, that she was going to die. I refused to believe her, but she was right. It was goodbye.

The difference between my mother and my mother-in-law decries comparison; the journeys of the aged are as divergent as their lives. My husband’s mother rambled from the large home where she had lived for some forty years with my father-in-law to, after his death, ten relatively independent years in a tidy up-and-down condo. The stairs finally persuaded her to relocate to a retirement home, called “assisted living,” with her own apartment, where meals

were provided and some nursing care was available. But for all its glossy patina, that “assisted” living place was mostly interested in assisting well-off elderly clients with disposal of their funds. The food was faux-gourmet, pre-prepared by a broad-line food facilities service, and consistently mediocre. The place suffered from poor ventilation and infestations of bedbugs – facts that were artfully concealed. The nursing care was casual and more or less limited to a stethoscope and a thermometer, along with speed dial to emergency services, ambulances readily carting the elderly to hospital for actual treatment, where they were treated with grudging attention, the murmured incantation of “bed-blockers.”

A bird-boned figure erect as her Scottish heritage, my mother-in-law grew increasingly frail, and it was only a short time before that inevitable fall and serious injury, a broken hip incapacitating her to the extent that the “assisted living” facility would not assist, and she had to be moved to a nursing home, euphemistically called a “compassionate care centre.” It claimed a beautiful, wheelchair-accessible patio area overlooking a natural ravine, but I never saw a single resident using that space. The nursing home had repurposed an old building, tottering on its legs worse than its residents, and it could not expunge the smell of death and defeat, the urine-soaked history of its defeated *dénouements*. Walking through its automatic doors never failed to make me want to turn and run away, jump into my car, and drive straight into a concrete abutment.

Visiting her was increasingly challenging as her world narrowed, from a room to a high-backed recliner chair to a fully mechanized hospital bed, connection made more difficult as her physical health declined. She was, like my own mother, cognizant and aware, with not a trace of dementia, but her body slowly renounced itself, curling into frailty as if she were a desiccated bird bone-cage. That gradual diminishment was a process as humiliating to her as it was dispiriting to us, visiting her as often as we could, bringing fresh flowers, photographs, reading the paper with her to keep her abreast of the world, bringing her tempting food beyond the potage she was offered, and trying to release her, as well as we were able, from the prison of her confinement. She too did her valiant utmost, but her physical ability did not match her desire, and eventually the very “care facility” that claimed to offer hope had nothing to give but a disconsolate solicitude.

The care home was a well-meaning but dreadful establishment; there is no other way to summarize its creaking fabric and locked stairwells, its smell of old potatoes and plastic drugs. Nothing is worse than a social hour hosting queasy renditions of “The Old Rugged Cross” sung to a half-tuned piano, or crumbs of aged slab cake meant to celebrate birthdays. The staff, mostly immigrants reduced to working at jobs they were overqualified for, were kind and generous, and their humanity did much to counterbalance the ghastly atmo-

sphere of the institution, but even their best intentions could not disguise the sheer immanence of life's closing doors or the attendant hopelessness of those who will never again feel direct sunlight on their faces.

I did not want my mother-in-law in that facility, and my husband and I did all in our power to persuade her to move to a private place in Calgary, close to us. She did not want to be in that nursing home either, but she resisted with every bone of her weakening body the idea of leaving Edmonton, the city where she had lived for more than 70 years. Her own stubborn cognizance refused to countenance moving, and her increasing frailty worked in tandem with a shortage of long-term care beds and a vilely incompetent health-care system. By the time we got her moved up the long list of "available beds" into a "nicer" nursing home, she was entirely too frail to be moved. I came to believe that decrepitude conspires with demand.

So I would leave each visit as dispirited as if I had been imprisoned with failure in a debtors' prison as maggoty as a Dickens novel. My own mother was full of fight, mouthy and resistant, but my mother-in-law's passive refusal was impossible to turn toward hope, and all I could do was turn the nose of my trusty little Jeep south down the Calgary Trail toward home, aware that the journey would repeat and repeat until she faded into her own extinguished breath.

But between 2008 and 2011, I always made one last stop on my drive south. I would pull into the parking lot of a retirement "home" located on the west edge of Leduc. With an increasing sense of relief, I would press the security intercom for #325, to be met with a whirl of industrious pleasure, Robert Kroetsch declaring, as only he could, "Let's go for ice-cream!" or "Let's go for a drive," brandishing a blue aluminum cane that seemed more for decoration than safety or assistance.

When I first heard that Robert Kroetsch (possibly the largest projection of writerly vitality in Canada) had relocated himself from Winnipeg to a retirement home in Leduc, I was quite simply shocked. I could not conceive of him in a closing chapter of life or of him voluntarily acceding to agedness or to any version of care. When I called and asked him what he was thinking, and how he had arrived at this migration back to Alberta, he answered with inscrutable and certainly poetic deliberation, "I am practising up how to get old."

He took to the life of a retirement home with the style of a man who enjoyed domestic ritual and regular meals and yet cherished his privacy and his difference from others. It was a new facility and seemed more secure apartment complex than care home, although nurses and doctors were on call. Most of the residents had no idea that he was a famous Canadian writer. He shared his meals with them in a communal dining room, played cards, and even went on excursions. One of his sisters, who lived not far away, helped with errands and laundry. He invited no one from the home, he said, having invited

me, into his small private apartment, where he had a comfortable armchair, a small bookcase, and a window overlooking a gas station across the road. In the bedroom was a desk with an ancient computer, and in the narrow kitchen, a table where he ate toast in the mornings.

It was difficult to discern whether he was happy. His own careful choosing of a place where he felt, it seemed, reasonably safe and that met his simple standards of care, was a measure of his awareness. He was a man of a generation not well acquainted with self-sustenance, and a kitchen was alien territory to him. While he was not disabled, he had, he told me, begun to fall, and he knew that he would need increasing medical attention. The bradykinesia and tremors associated with Parkinson's were growing worse, and his own relentless attention to poetic detail certainly attuned him to the increasing frailty of his body. He had returned to the Parkland of Alberta, the place that inspired his brilliant poetry and fiction; he had company if he wanted, family close to him, and he appeared to face the spectre of "old" head on. I attribute to him a clear-eyed realism in facing old age, but that could be my own invention, one I rely on to comfort myself. He continued to write, he had myriad visitors, and he loved excursions and trips.

One summer day, sitting on a bench outside his favourite ice-cream source in Leduc, he said, "I've found the title for my new book of poetry. Guess what it is!" And when I waited, expectantly, he announced, with a gleeful relish that encompassed all the pleasures and regrets of a life brimful of event, if not quiet happiness, "*Too Bad!*" We both burst out laughing, aware of that ironic phrase, its emphatic rejoinder, its sheer audacity, as if he were saying to age itself, "Just don't go overboard with the gratitude or the constative evaluation." Life perhaps regrettable but now beyond retrieval.

And when he died suddenly, just before his 84th birthday, in an automobile accident, he seemed, for all his cane and his Parkinsonian tremor, younger than any of us, more prepared, more adaptable, and more aware of the conjunction of care with independence. My visits with him in those last years revealed no resentment that he was growing infirm, that he needed to live in a care home, that he was alone, and probably lonely. We played with language, told one another stories, and talked about literature; his enthusiasm for his own long relationship to writing never faltered, and so, although I suspected he was deeply sad, he performed an ongoing role with practiced gusto.

His last reading, at the Canmore artsPeak Literary Saloon on Sunday 19 June 2011, was met with a standing ovation for a poem on risk, and he said to the organizers later that evening, as they report without a trace of irony, "If I die now, I'll die happy." Just two days later, he was killed.

My triangle was broken. All three of the old persons I pilgrimaged toward and away from are dead. I grieve them equally, if in different ways. Their staunch engagement with life despite the challenges of aging, and their own

particular rejections of and experiences with care were salutary, yes, lessons about how we “practise up” to get old. Their associations with care, whether to accept help or to resist, their passivity or their activity, declared far more than their characters but gestured toward that baffling liminal territory between one life and the next.

They waken me sometimes, from a dream of my own care in my old age, all insisting they had little choice, but were mere pawns in the wager of time against time.

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# Home Interrupted

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*Monique Lanoix*

"Do not worry; we will take good care of him.  
We take good care of *our* residents."

These words are meant to reassure me and help me to move on, whatever that implies, as my husband enters long-term care. However, years later, I still hear them and they continue to instill fright and send a chill down my spine, just as they did when I first heard them. At this initial meeting, I wonder: "Who are you to take good care of him? And why do you say '*our*' residents? Those are individuals; they are not yours, no one gave them to you." And so this is the first part of entering long-term care: a process that is meant to alleviate my burden by effectively removing my husband from my care. Granted, I could not take care of him at "home," so here we are in the hallway of a nursing home. He is unaware of what is going on, and I am in a kind of shock. I say "a kind of shock" because the journey from the car accident to this facility has taken us to a variety of medical settings. Nevertheless, this new setting now presents itself as a place of permanence. The comfort I may have found in the transitory nature of the other medical settings is removed by the reality of this new "home."

This is a public long-term care institution: funded by the Quebec provincial government and subject to provincial standards. Nevertheless, the physical space is old; it looks like a hospital; the shared room in which he will be spending much of his days is too small to accommodate him and another resident together. My husband will need to be moved from the original placement, and the other residents will simply be shuffled to other rooms so that he can be transferred to a larger room.

It seems that, in this place, "a room of one's own" is granted only on a temporary basis. In any case the rooms are rather interchangeable, and they do not have much wall space to accommodate personalization. It is hard to claim ownership of such spaces, and it appears as if very few residents have tried to do so. Really, only one's bed is "one's own," and I suspect this is more for sanitary reasons than actually granting ownership to any one resi-

dent.<sup>1</sup> This place appears temporary in a permanent way; I've heard it called "God's waiting room." I can only presume that the thinking goes like this: why encourage ownership, when the resident is expected to depart? That is the one certainty – death – although the timing might be unpredictable. As in the departure lounge of an airport, when you leave, you leave nothing behind. It just makes everyone's life easier that way. The atmosphere is one of instability amid un-change: there is the recognized fragility of being, yet nothing is done to support it or even grant it dignity. Here, this fragility is a fact of life that must be accommodated. It is a source of employment, although those for whom one cares continually shift: different bodies, same care.

## DISRUPTION

It may appear incongruous, yet within the formidable institutional structure that is long-term care, transience remains a permanent feature. Some of the literature on long-term care institutions uses the concept of liminality to capture the atmosphere that reigns in such locations. As Leibing et al. explain in their article on living spaces and older individuals, liminality can be used to denote a transitory state, of being betwixt and between, or it can also denote a static state in itself (12).<sup>2</sup> For these authors as well as others who have used the concept of liminality to examine facets of long-term care, the central idea is one of uncertainty, of not having a specific location.<sup>3</sup> Liminality indicates a grey zone of ambiguity, of not being anywhere in particular for any set length of time. If the institutions tend to be architecturally similar and the care rather uniform, there is always a feeling of uncertainty. In part, this is because the people inhabiting nursing homes are usually in the last phase of their lives. So when a resident dies, there is often no official acknowledgement of his or her passing. All of a sudden, the person is no longer there and soon someone else occupies the room.<sup>4</sup> It makes for a fragile and shifting community, where loss

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**1** | In Quebec, the actual bed is the property of the long-term care residential home. When a resident moves or dies, the establishment keeps the bed.

**2** | It should be noted that the authors' discussion focuses on assisted living places and that institutions are regarded by their respondents as scary places where all individuality gets lost.

**3** | For example, in their study of privately paid caregivers in long-term care institutions in Ontario, Daly et al. use the term to refer to those individuals' location in the policy-family-market triad.

**4** | If this was my experience, it is not the practice everywhere. Some nursing homes have a memory book at the entrance of the building where the life of a resident can be celebrated and the loss acknowledged.

lurks but remains unacknowledged. Perhaps this silence is meant to diffuse the fear that death is always near. For the staff, it may help them normalize death as an inevitable component of their routine of care.

The status of most people in residential care is that of outsiders, even if they remain within society. They are not completely outside the flow of society, but they are certainly marginal to it. The time of residence in long-term care is expected to be rather short for most residents.<sup>5</sup> This may reinforce the sense of liminality, and it may be an excuse for the lack of effort to redress this feeling. Nevertheless, for those who are older it becomes an inevitable phase of life, even if unpleasant, especially since we are living much longer. However, my husband's situation defies even this marginal acceptance. He was in good health, he had a job, and he could be readily perceived as contributing to society. Now, at barely 40 years of age, he has suddenly become a broken, unrepairable human being who is institutionalized. As one care provider told me, he is expensive to the system: he has been in a nursing home for a long time, requiring the maximum number of care hours.<sup>6</sup>

At this point, I need to explain how my husband and I came to such a juncture, so I will now start the story from the grim beginning. Some years ago, my husband and I were in a car accident. He suffered a severe traumatic brain injury that has left him quite disabled, both physically and cognitively; he requires care for all his needs. After more than four months in acute care, he was transferred to a rehabilitation centre, where he stayed for more than six months. The practice has since changed. I doubt that a person with his level of injury would be offered any rehabilitation today and, if they were, it would be for a much shorter time period. Toward the end of my husband's stay, the rehabilitation team concluded that he would not make any appreciable gains and would never regain anything close to a functional status. So he was eventually discharged with the goal of sending him to a long-term care institution. Since placement was not immediately available, he was moved to a long-term care wing of an acute-care hospital – again another disruption, although one that is fairly routine.

It is often the case that a patient goes from an acute-care setting to rehabilitation and is then sent to his or her prior home. That had been the process that I had followed after my own injuries. The rehabilitation centre was not meant to be a homelike environment; it was a deliberate attempt to simulate home in order to prepare patients for their return to their original abodes. For example, during my rehabilitation, I experienced simulated stairs, bikes, and kitchens in

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**5** | The average length of stay in long-term care is 18 months (Macqueen).

**6** | In order to reside in a long-term care residential centre (CHSLD, centre d'hébergement de soins de longue durée) in Montreal, the maximum number of hours of care is three per day. See Gouvernement du Québec.

order to regain functionality. These substitutes were obvious and were usually embraced, as they held the promise of returning home: necessary steps to regaining some form of normality. However, in the case of my husband, there was no such hope. So we had to envisage leaving rehabilitation to go to a new place of faux permanence – an institution. This meant having to adjust my goal and hope of sharing a home with him.

Throughout the course of my husband's rehabilitation, the practitioners at the centre watched me in order to gauge how I would cope with the realization that home would have to change meaning for me. They encouraged me to think of my husband as finding a place where his needs would be met, and that I could then be relieved of any worry or burden of having to care for him. They did not frame the long-term care place as an eventual homelike environment, but rather as a place where he could be cared for. The disruption at this time was the expectation that my life and that of my husband could be neatly separated. I could continue to live as I had previously lived and function normally, and he would simply become the institutional charge of the medical system. There was little room for negotiation or for any other way of including my husband into the story of my life without this very permanent rupture. I felt an imposed sundering of our lives. To think otherwise was perceived as abnormal: why would one continue to have an extended relationship with an institutionalized other? Yes, there could be regular visits at holiday and significant times, but our lives would have to take separate trajectories and intersect only briefly at those times.

From the hopeful world of rehabilitation then came the discharge to whatever acute-care hospital had the means to care for a patient with total needs awaiting long-term care placement. This transfer was upsetting, but the experience of rehabilitation had been so terrible that it was almost a relief to be out of a setting where one was constantly reminded of being a failure. The head nurse of the long-term wing was not thrilled to have "heavy patients," as it meant more staff were needed, and I am sure she had to deal with budget considerations. She was eager to have him placed as soon as possible, and she did not react well when I refused the first place that came open. My refusal was based on the location and accessibility of the long-term care establishment. It was important to me that I could easily reach my husband's new permanent living space, and access to public transportation played a key role in my decision. It took over six months for him to get placement in a nursing home that could meet our needs. When the time came to move to the long-term care institution, the break from the acute-care wing was less problematic, as I had been told many times that it would be temporary, but I did have to say goodbye to care workers who had been kind to us. Always on the journey through these different settings, we found leaving some of the practitioners to be difficult.

At the time of my husband's admission to the long-term care centre, I was not particularly disturbed by the medicalized environment; in fact, I was used to it. I think that if the nursing home had been a more homelike and friendly environment, I might have been more unsettled because it would really have appeared as if my husband was going to have another home and I would potentially be excluded. As it was, the medicalized setting was simply a continuation of what I was used to.

## A DISTURBING PRESENCE

In Quebec, as in many jurisdictions across Canada, nursing homes or, more accurately, long-term care institutions provide care according to the hours of assistance required by individuals. Residents are housed according to the hours of care required and not according to age, which means that some institutions can have heterogeneous populations.<sup>7</sup> Given that individuals regardless of age may require extensive care, there have been recommendations to have separate places where younger individuals can live (Association québécoise d'établissements de santé et de services sociaux). Unfortunately, my husband is so severely disabled, and at that time he was not taken to be aware of his surroundings, that such an option was not even considered. In order to give a more complete picture of the situation, I will at this point clarify his cognitive abilities, as those are hard to gauge in the case of a head injury. He recognizes me and can answer simple requests with a yes or no. He can be verbal, but he needs to be calm and can get very agitated quite easily. This is typical of an individual with a head injury, especially one in which the frontal lobes are damaged. Such individuals have difficulty dealing with any new stimulus.

When he first entered the long-term care institution, he was a bit of anomaly as an individual with a severe traumatic head injury. Most residents were older or, if they were younger, had degenerative neurological conditions such as multiple sclerosis and did not have major behavioural issues such as yelling or swearing. Coping with someone with a head injury requires specialized care, which was not available since the institution was focused primarily on dealing with physical needs.

At first, the personnel were very nice and certainly had empathy for a younger person who had suffered such a tragic fate. Their lack of training did not help them understand the negative sides of a head injury, however, and at times my relationship with them was quite strained. I was spending a fair amount of time there initially. Since they saw their job as taking care of someone who

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7 | For a discussion of different types of long-term care institutions in Canada, see Banerjee.

could no longer function, my presence was superfluous and they could not understand what I was doing there. As far as they were concerned, I should simply go on with my life and leave my husband behind; I was hanging on. If my presence was tolerated and even encouraged in the rehabilitation setting as part of my husband's recovery process, in the nursing home I became an intruder, a disruption to the flow of care.<sup>8</sup> However, I was not ready to go on with life without somehow keeping my husband in it. In addition, I was not convinced that the care he was getting was adequate. My problem was to negotiate the seemingly irreconcilable goals of keeping an eye on my husband's care and living my life as a functional individual in the normal flow of society.

If finding and claiming my place within the nursing-home context was difficult, it was also a challenge in my regular life. While I was writing my doctoral dissertation, my schedule was fairly flexible and I did not have to account for my time. However, when I started teaching, when asked about my personal life I would explain that my husband was in a nursing home. This declaration was usually met with awkward silence. I took the decision to simply stop mentioning him or my visits, as it was an unsettling reminder that life does not always progress smoothly in expected ways.

## **TWO-HOME SYNDROME**

When a close family member is institutionalized, those who are left behind are faced with an incomplete or somewhat broken home. I have tried to recapture the spirit of home in the location where my husband is living. I have thus become someone with two homes: one that was the home I furnished and inhabited with my husband and where he no longer lives, the second a place where I can sit in an uncomfortable chair and share small pleasures with him such as watching television. In addition to the awkward room arrangement, which often means that one is sharing a room with a stranger and his or her family, the physical surroundings are uncomfortable in this new living space. I have only a small chair to sit in, and since my husband spends most of his time in bed, the room has become the primary framework of life.

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**8 |** While often unrecognized, families play an important role in the care of institutionalized family members. In their study, Keefe and Fancey recommend integrating family members in the care structure. In his review of American long-term care institutions, Gaugler explains that programs have been put forward to improve family involvement as well as relationships between staff and family. However, in my experience, such programs have not been put in place in Quebec. The only change I have witnessed is the fact that family members are invited to participate in team meetings concerning the care of family members. These meetings take place once a year.

I call this the two-home syndrome: one is never quite at home when one is at the old home, and the other place is not really a home. The negotiation of the disruption of home into two places may take a while to accomplish. One can try to make the second homelike environment somewhat pleasant, but it always has to be negotiated through institutional structures and lack of privacy. So for some time one may be in a liminal space: never at home in any of the two homes. It can certainly be negotiated eventually, but it takes both time and conscious effort. I would say that the rupture is never mended but the situation can become normalized. One learns to live with one home and another good enough home where the family member lives. It becomes an interruption that can be navigated.

My solution at the time of my husband's arrival at the long-term care home was simple: since I could not do much about the surroundings, I tried to make his room homelike by being there and sharing time with him. I understand now that my presence was disturbing to the staff. They were used to going about their routine unfettered by intruders, and my constant presence somehow interrupted the flow of care and their patterns of work. Nevertheless, I believe that my husband was aware enough of his surroundings to know he was in an odd place, and that my presence was at least a familiar and stabilizing element in the confusion of his new institutional life.

As I understood it then, and still understand it now, home is about being close to loved ones; it is about sharing space where one feels relaxed with close others. If I could be close to my husband and he felt close to me, I believed that I could still capture an essential element of home, even if the surroundings belied home and screamed "institution." If my home came to an abrupt end with the car accident, my seeking and trying to build "home" continued despite the institutional flow of life that was taken to somehow encourage homelikeness, without ever actually achieving it.

## THE EBB AND FLOW OF CARE

Over the years that my husband has been living in this institution, changes have taken place. This particular long-term care centre sits at the crossroads of institutional transformation. That is, the centre has a long history of being an institution for the "sick and destitute incurables," as an account of the centre explains (Grace Dart Extended Care Centre). At the beginning of the last century it was a hospital for tuberculosis, and then in the mid-twentieth century it became a centre that accepted individuals who could not function without care in mainstream society. Since at that time persons with disabilities were institutionalized far more routinely, some of the residents who had been there for a long time would not be institutionalized today. It made for a varied

community of residents. However, at the end of the twentieth century, social conditions for institutions started changing. The Quebec ministry responsible for long-term care saw nursing homes no longer as institutions but rather as a *milieu de vie substitut*, or a homelike environment (Ministère de la Santé et des Services sociaux). Therefore, the institution where my husband lives has had to change or at least try to adapt to this new philosophy.<sup>9</sup>

As this shift swept through in the late 1990s, long-term care institutions were under pressure to become more homelike. Recognizing that as a society we were living longer and that many older persons could not remain in their homes, the focus of the ministry was to de-institutionalize long-term care centres or at least make them feel more homelike. In part, the impetus for this alternative homelike environment, or *milieu de vie substitut*, is to encourage residents to adapt to a new life. These individuals should still feel as if they were in a home and not in a hospital, which is what most long-term care institutions evolved from. And the emphasis on “homelike” is meant to encourage this new life to be as normalized as possible. It is also an explicit recognition that the person still has a life to lead; she or he is not simply in “God’s waiting room”. This is a good way to think about the new phase of life: an active part of living. Instead of waiting for death, the focus on “homelike” puts life as the main concern. And since the majority of residents are long retired or, in any case, elderly, and were probably doing much of their living in their homes, home was the primary place where they spent their time. Home is a significant emotional tie to life, at least in term of physical surroundings. So it made sense that long-term care institutions should strive to create a homelike feeling within their physical surroundings.

This is what happened at my husband’s institution. If the centre could not change its overarching physical structure – the corridors are long and the rooms are hospital-like – it could at least become more attractive. The rooms were painted and some of the offices were changed into larger living rooms with television sets and communal tables. The effort was commendable and seemed to make some residents and family members happy. At the time of the initial renovations, I was a member of the residents’ committee, and the president of the committee, who had lived there for quite a long time, was most thrilled with these improvements. The effort was designed to change the immediate surroundings of the institution: what could be seen by the residents in their

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**9** | As stated on the web site, “The mission of the long term care centre is to offer, in a temporary or permanent fashion, a substitute home environment, housing services, assistance, support and surveillance services, as well as rehabilitation, psychosocial, nursing, pharmaceutical and medical services to adults who, due to their loss of functional or psychosocial autonomy, can’t reside in their natural home environment, despite the support of their entourage” (Grace Dart Extended Care Centre).



daily routines. I must say that it certainly was more pleasant to walk around and to be able to watch television or simply sit around a table.

Such changes signal a move away from characterization of long-term care institutions as primarily liminal spaces. The changed interior is meant to anchor life in the everydayness of a facsimile of home; thus, it encourages the view of long-term care as a phase of life. I think the effort is quite notable and has been in place in most jurisdictions in Quebec and across Canada, depending on budgets, of course. There is nonetheless still an element of liminality in the sense that long-term care, in most cases, is the final destination before one dies. This can never be erased, since the population that inhabits these centres is taken to be at the final phase of life. However, the emphasis on the pleasant surroundings tries to erase at least some of the negative connotations of moving into a long-term care centre. In addition, the renovations and small improvements are part of an attempt to move away from long-term care institutions as “total institutions” (Goffman).

Transforming the immediate physical surroundings is an important first step, but it has remained the only step. If the surroundings play an important part in creating an atmosphere of home, there are other facets to institutional care that should change also. Institutions are not simply a physical structure; they are also a place where people work and, particularly in the case of long-term care centres, live.

The centre where my husband lives is regulated by the clock. It is certainly the case that our lives in general are regulated by going to work or school at set times and eating according to a schedule, but this regimentation is even more pronounced in institutions. And the interruptions are usually out of the resident's or family's control. For example, the assistance that takes place regularly at set hours in order to maintain efficiency produces small but continuous disruptions to the flow of life. Sometimes, the staff can help someone if they ring. However, care is scheduled in rounds. This is a direct consequence of the medicalized environment from which long-term care originates and in which the nurse goes around giving patients their medicine according to a set schedule. Similarly, in institutions, at set times, care workers go from room to room to reposition the resident or check if the resident needs to be changed. Despite the discourse surrounding the importance of home, a medicalized structure still prevails in long-term care facilities.

In addition, efficiency regulates institutional care, and it is perceived as most efficient if certain caregiving activities take place at set times. As one resident told me, “In effect what happens is the staff all gets going at the same time and then they all sit down at the same time.” Individuals who have mobility impairments need to be repositioned every two to four hours to prevent pressure wounds. Therefore, when residents need to be repositioned, institutional efficiency demands that it be done room by room, starting at a set time each day

and ending at roughly a set time. This in part fulfills the goals of long-term care, which include providing personalized care in a safe and secure environment, yet it is at odds with the goal of providing care in a familial atmosphere.<sup>10</sup> Perhaps it is too much to ask for, given the medicalized environment in which care takes place. Still, the notion of the “not-home” is thus continually being suggested by the small and continuous interruptions that arrive at set times. Instead of punctuating special times of day, such as lunch or dinner, they often disrupt the daily flow of life.

When they have to provide care, some of the care workers or orderlies will be polite upon entering the room. They may announce that they are coming in to check on the resident, but very often, as is the case with my husband, they will just come and accomplish whatever needs to be done. They are on tight schedules, so they do not have much time to chat.<sup>11</sup> When someone has impaired cognition, such as my husband, it may simply be assumed that the person does not really understand what is going on, and actually telling him what is going to take place will be perceived as a waste of time. As one care worker said to another worker when speaking about my husband, “Why bother asking him? He is just going to swear.” This in fact demonstrates that the care worker does not really know how to handle a person with a head injury and has not taken the time to understand what is going on. So-called personalized care is actually rather impersonal, and this is in part for the sake of efficiency. It is not *personalized* care per se but *individualized* care in that every individual gets cared for personally. In that sense, it is individualized care: every individual receives care that is adequate for him or her. However, it remains impersonal as the needs of each resident are not contextualized but rather remain generalized, to be taken care of at regular and predictable times.

This broken flow of life affects the quality of homelikeness in a couple of ways. These small interruptions serve as reminders to residents and their families that they are living in a facsimile of home where the likeness is in fact quite superficial. If a resident is watching television, he or she can be interrupted by the rounds. That is a fact of institutional life that cannot be controlled, and it is often what most people fear about institutions: they become objects of care. The individuality of the resident gets lost in the timetabling of care. As I sit there with my husband quietly, I am always aware that at 2:30 or so, someone will come to reposition him. If the flow of life is often disrupted in regular life, it becomes ingrained in institutions. There may be some efforts to accommodate individual needs, but if such needs are not medical, are just

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**10** | As the Association québécoise d'établissements de santé et de services sociaux explains: “Favoriser l'aménagement de milieux de vie sécuritaires, personnalisés et empreints d'une atmosphère familiale.”

**11** | For a critical discussion of paid care work, see Lanoix.

a matter of preference, and cannot fit neatly into the regularized flow of care, they remain unmet.

In addition, the structure of care is such that a person's most intimate care is provided by persons who will usually remain strangers. In some ways that can be liberating, but in other ways it reinscribes the notion of not-home. Some individuals may prefer to get care from persons who are not family; in that way they preserve the intimacy of the bond with the family member. Even in such cases, the caregiver will be someone who will become familiar. However, this does not really happen in institutions. Workers must remain professionally detached, and it is often the rule of establishments that a certain distance must be maintained.<sup>12</sup> It is a difficult negotiation to make, and care workers are not supported enough in this. Workers respect the privacy of the medical dossier, but at the same time, the structure of care provision has an impact upon the privacy of residents. One is very seldom alone in a long-term care institution. The boundaries between oneself and others, either workers or other residents, have to be constantly renegotiated. Again, this aspect of institutional care continually reinscribes the not-home. An individual has to somehow carve out a space of homelikeness amid the constant pressures of becoming an institutionalized object of care.

## FRAGMENTS OF HOME

In conclusion, despite the best intentions of regulators, there are many ways in which the idea of home is disturbed. First, quite obviously, when a partner has to be institutionalized, home is no longer a single place. I had to negotiate my home without my husband and this other place where he was living. However, this other location is also a place where people work and other people live. It is an odd living arrangement, and it is difficult to understand one's place within such a setting. I could attempt to see myself as giving some care or participating in my husband's care, but it became apparent that I could not really relate to the people who were caring for my husband as co-caregivers. I was seen as a family member that made demands. I was like a boss in a way and was often perceived as a hindrance to the care practices that were in place. I was a disturbance; my mere presence needed to be accommodated, and not every worker felt particularly good about that.

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**12** | It is not that care workers do not care; they are simply not given the *time* to care. For a discussion of nursing-home workers, see Diamond. Although dating from 1992, this book is still relevant and remains a lasting contribution to the understanding of care work.

As a family member of someone living in long-term care, I have become particularly aware of the manner in which the trope of home functions as a way to remind me that my husband is living in an alternative homelike space. This space is provided as a way of humanizing his care, but it remains fragmented and ultimately inauthentic. If some pieces of homelikeness can be recuperated, the apparatus of institutional care can, in turn, easily dissipate them. This can only result in a continuous shift between home and not-home. In addition, the institutional care he receives is regulated in a way that reinscribes his body as disabled and as Other, especially since he is cognitively impaired. Because he cannot voice his needs, he is taken to be apathetic and uncommunicative. This means that he is physically repositioned at set times. His caregivers do not feel they need to engage him; they can get away with entering his room and mechanically providing care. The flow of his daily life is punctuated by care provision that arrives at a set time and not according to his needs. Within an institutional setting, even if it purports to be homelike, this acts as an indicator that one is an object, rather than a subject, of care.

Institutional interruptions become the norm in a facsimile of home. The daily activities of care continually reinscribe the “not-home” within the living environment. Because the focus on “homelikeness” targets the physical surroundings of long-term care institutions and not the manner in which workers interact with residents, those institutions cannot be “homelike” and much less a “home.” Likeness cannot be produced and maintained by the physical environment alone; it should be inscribed in the practices of care. Therefore, to be at home should be embodied in these practices of care, which in turn support the flow of daily living and do not merely serve to disrupt it.

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# A Place for Dad

## One Family's Experience of For-Profit Care

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Amanda Barusch

I'm having a hard time manufacturing words right now.

Those were the first words Dad spoke to me over the phone when he found himself heavily sedated and physically restrained in the local Intensive Care Unit (ICU). He sounded drunk.

My father was diagnosed with probable Alzheimer's in 2007. He was 83 years old and had lived for the past 30 years or so on five hilly acres in a "quarter-million-dollar-fixer-upper" in Northern California with his second wife, my step-mother, Catherine.<sup>1</sup> Like many who receive the diagnosis, Dad's cognitive difficulties crept up on him. Never terribly precise, Dad's stories became even more vague and inconsistent. Then he developed "sundowning syndrome." Common among people with cognitive impairment, sundowning describes the exacerbation of symptoms in late afternoon or evening (Khachiyants et al.). Catherine noticed that Dad didn't know who she was when they sat down to dinner. He wouldn't ask her name outright but pestered her with questions: "Where are you from?" "Are you married?" By the next morning, the problem was gone.

Later, the loss of names and identities became more pervasive. Once I called the house while my brother was visiting. Dad took the phone into the bedroom and whispered, *There's some guy staying here. I can't figure out who he is. So, I go through the waste paper in his room when he's not around. I think I'll find an envelope addressed to him and figure out his name.* Dad's cognitive difficulties were more severe than I'd thought, but I marveled at his clever coping strategy.

Linda Clare examined the coping strategies of 12 older adults in the early stages of Alzheimer's. She described the tension between "developing a fighting spirit" and "coming to terms" (139). In Dad's relationship with Catherine he provided the fighting spirit. She managed the coming to terms: setting up a

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1 | All names used here are pseudonyms.

strict regimen of vitamins and supplements designed to forestall the inevitable, removing the knobs from the stove controls so he couldn't burn the place up, cutting off electricity to the power tools in his workshop, hiding the keys to the car.

The tension between these two positions played out in their relationship. After my brother's stay, I went for a visit. Dad pulled me outside to their deck, overlooking a dry California meadow. He said, *You know ... the funniest thing ... I used to be married to a woman with exactly the same name as that one in there. But the one I was married to was younger and prettier.* I laughed, "Dad, you'd better not tell this one about the other one," and tried to persuade him that he was actually married to "that one in there."

Catherine's emails were peppered with reports of Dad's misbehavior. She brought in a live-in male caregiver, but Dad didn't like the guy. He called him *Stan the man*, swore at him, and threatened to key his car. I figured Dad was jealous. Then one day he picked up a two-by-four and chased Stan off the property. I came to dread emails with the subject line, "Your Father."

Catherine arranged a trip to Sedona, a town in Arizona they both enjoyed visiting. But the day before they were scheduled to leave, she wrote,

Your dad begged me in tears to cancel the trip. He said he knew he was an old man and he wanted to spend all of his remaining days right here, in a place he loves, with the cats ...

So the trip was cancelled.

Catherine hired a daytime caregiver, a woman named Marilyn, whom she located through Senior Network Services, a non-profit "community resource agency" that relies primarily on government funding provided under the Older Americans Act. Senior Network Services maintained a registry of home-help providers who had passed criminal background checks. Marilyn had recently lost her best friend to Alzheimer's and knew how to manage dementia.

Still, as I told my friends, "Early Alzheimer's is not that bad!" Catherine and I marveled that my Dad, who had accumulated more than his share of resentments in life, had forgotten all about them. He was gregarious and more pleasant than ever. Three years after diagnosis, Catherine was still coping fairly well. Marilyn came on weekdays to take Dad to appointments and exercise classes, and Catherine was even able to get some work done. In August of 2010 she reported,

We just adopted two 5-month-old tiger kitties from the collection at the Farmer's Market. They're litter mates, one male and one female. I think their names will be Mickey and Mocha. Lively little critters ... Ten days later, One kitty's name didn't stick. Your



Dad calls the little female “Spider,” so I guess that’s her name. Mickey is sometimes “Monkey,” so maybe that’s his name. Or Mickey the Monkey.

The last weekend in September, Catherine asked me to keep Dad busy so she could get some things done. He and I set out to plant some tired-looking bay trees that Catherine got for free from a nursery. We hauled trees and water up the hill in a wheelbarrow. I dug holes with the old post-hole digger while Dad watched and gave the same instructions he’d given 40 years before when we built a corral for our new goat. Dad set up a drip irrigation system so the trees would survive those dry autumn days.

The following week I was scheduled to teach a workshop in New Zealand. At San Francisco International Airport I checked my email to find a message from Catherine:

#### Your Dad: An Update

Early this morning your Dad fell after getting out of bed ... I was in the other room and heard the crash. He was on the floor, breathing but unresponsive for a while, then did come around. I called the paramedics to come and lift him back into bed. He complained of a fierce headache, so I think he hit his head when he fell.

Later this morning Marilyn took him to Urgent Care to get a prescription for cough medicine (they wouldn’t prescribe without seeing him again). Dr. Kim at Urgent Care said your Dad has worsening pneumonia, worsening mental state, lower oxygen level. Also, he is very unsteady on his feet, and has to be assisted to walk. This is all so unlike your Dad!

Only a few days before, Dad was hauling water up the hill and playing with his cats. Now he was being assessed for hospice care. Catherine did not plan to treat the pneumonia because Dad had signed an advance directive requesting that no heroic measures be used to save his life. “But,” I said, “antibiotics are not heroic measures!” “Oh yes, they are.” Catherine had shown me the directive when Dad was initially diagnosed. I even read it. But, contrary to the advice of experts (Brown), we never really discussed its implications. This set us up for a difficult conversation that culminated in Catherine saying, “Amanda, you are in denial. Your father is dying.” My brother Daniel and my husband Lucas both agreed with her. So I got on the plane, fully expecting to be summoned back by my father’s death. But Dad didn’t die. He didn’t even have pneumonia. Or, if he did, it must have been viral. No. Dad rallied, but his abilities were diminished. Catherine wrote:

Turns out your Dad’s cognition took a serious hit. He can no longer find the bathroom by himself ... At midnight last night he got up and was wandering around the house in his pajamas. He was carrying a pair of shorts in one hand and my watch in the other hand.

He said he needed to poop ... I led him to the bathroom, and waited for him, to guide him back to bed. But somehow he must have forgotten how to use the toilet, and apparently didn't pull down his pajama bottoms. So he dropped a large loose load in his pajamas and also urinated through them into the toilet. He wasn't aware he had done any of that ... I'm seriously thinking placement.

Dad's cognition improved a bit, but as winter approached Catherine developed severe colitis, which her naturopath told her was stress-related. Then she tripped over one of the cats and broke her foot. Later, she explained that with these two events she "permanently lost the ability to pursue two of my major interests: hiking and cooking."

Dad's problems with incontinence continued, and his outbursts became more frequent. As an academic gerontologist, I knew the predictors of institutional placement: cognitive difficulties (particularly when accompanied by angry outbursts), lower functional capacity (particularly incontinence), and caregiver burden (Haupt and Kurz; Luppá et al.; Rozzini et al.). I set out to find a geriatric care manager who could help us make tough decisions.

Care managers are not licensed in the United States, but a non-profit association (NGO) called the National Association of Professional Geriatric Managers (now Aging Life Care Association) provides certification and maintains an online directory of its members. That's where I found Sharon Kenway, a registered nurse and certified care manager, who held an "advanced professional" membership in the association. Sharon did a complete assessment of Dad's status and facilitated several pleasant family conference calls that led to clarification of issues, but no decisions.

## **DECISION**

Rather than place Dad in a facility permanently, Catherine decided to seek a temporary respite placement for a couple of weeks. Sharon recommended an assisted-living facility called Munio:

If you are open to talking with Rachelle at Munio, it might be a good place to look and have a conversation so you then have a good idea of some of the special care opportunities to look for in the other care homes. Munio is a leader in memory care and Rachelle is well respected and has been in her position for an extended amount of time. I told her you might be calling.

But Catherine wanted to send Dad to Marilyn's home for a while. Dad had an excellent relationship with Marilyn and it was difficult to arrange for the TB test required by licensed facilities. Sharon did not approve:

I'm not saying that you cannot choose to do this, but I caution you to look closely. Is Marilyn available 24 hours/day and prepared for any confusion at night? Do you know that the meals are prepared appropriately, I would much prefer that you consider having Marilyn go with [Dad] to a licensed board and care home or assisted living facility ... there ... you know that bathrooms are safe for him and that he has appropriate sleeping arrangements.

So Dad moved in with Marilyn and her husband, and Catherine cut off communication with Sharon. This was the second time Catherine and I had disagreed about Dad's care (the first being on the question of antibiotics for his pneumonia). Despite our gratitude and affection for Catherine, I found it difficult to accept that as Dad's wife and as the first person listed on his medical power of attorney, she was in charge. Perhaps sensing my disapproval, Catherine advised me of her decision after the fact:

Subject: Your Dad is Asking About You

Your Dad is staying with Marilyn for a few days while I get some projects taken care of here. She says he would like to hear from you, just to know that someone is "checking up" on him (he thinks I'm away for a few days). So, if you get a chance, Marilyn's cell number is ...

Thanks.

Initially, the arrangement worked well. Dad was cheerful and focused during our daily phone calls. He got along with Marilyn's husband, and Marilyn didn't mind his getting up in the night. At least that's what she said. Catherine enjoyed having the house to herself and catching up on her sleep. Then, one night, Dad decided to walk home. This was not uncharacteristic. He often took long walks through the hills of his neighborhood. But this wasn't his neighborhood. A rescue squad located Dad a few miles from Marilyn's house and brought him back perfectly cheerful and healthy.

Dad returned home and was there for eight months before Catherine once more needed respite. During this time, Catherine wrote:

As summer wanes the flowering plants on the deck bloom less. I do more deadheading to try to prolong their blooming, and I rejoice in the occasional late burst of color. But it all feels a tiny bit desperate and ultimately futile. Caring for your dad brings a similar feeling of desperation and futility, and also a similar rejoicing in any small sign of normality, of reblooming. Then I wonder if I am just interfering with nature's course, if I am out of step with the rumbling universe.

She described her conundrum as Dad's "care partner:"

The more I do to support your Dad's happiness and health and cognition, the longer I delay his inevitable decline; and the longer I delay his inevitable decline, the worse toll it takes on my health and wellbeing. Yet, emotionally and morally I cannot, and will not, do otherwise. This is my path, and I need to find a way to follow it with grace. I feel caught between a rock and a hard place, and it has been tearing me apart.

Catherine arranged to attend a week-long retreat in a nearby community. My brother and I would stay with Dad, and Marilyn would be available to help us during the day. As time for her departure drew near, Catherine prepared a 40-page book of instructions and emailed periodic addenda:

Oh, and one other thing: the coffeemaker is history. Twice your Dad almost started a fire with the carafe, so it's too dangerous to have around. You'll have to make do with manual drip, a la barista.

Our week with Dad was uneventful. We had coffee in the morning, walked down to pick up the paper, played with the cats, puttered in the yard. Dad and Daniel talked, and I took notes. We went out for ice cream and Dad remembered Catherine's birthday – sort of: *September 27 ... that's somebody's birthday*. So we bought a card. Nights were disrupted by the motion-sensitive alarm in the bedroom, which buzzed whenever dad left the bed or a cat walked by.

Several months later, when Catherine decided to go on another retreat, she asked Marilyn to stay with Dad. This retreat was not so restful, as Catherine wrote:

What happened that triggered the colitis was that the Sunday before I was to go [on retreat] your Dad experienced what seemed almost like a psychotic break. We were without electricity most of that rainy day, so our normal routine was off ... He was unusually irritable at dinner, wouldn't take his supplements, and I made the mistake of arguing with him about it. Whereupon he collapsed on the table with wracking sobs, saying he was lost. The rest of the evening he varied between loud anger at me and such devastating unhappiness that at one point he collapsed in my arms and I had to lower him to the floor. So the whole time I was away I worried about him.

Catherine put Dad on the waiting lists of several assisted living facilities (they are called Residential Care Facilities for the Elderly or RCFEs in California) that met her criteria: activities to keep Dad busy, a pleasant setting that was convenient to their home, and the availability of organic food (though she eventually compromised on the food). Munio was not among them. Two weeks later, a room became available at a nearby facility, and Catherine put down her deposit. She was required to furnish the room and provide linens and blankets.

Dad would need a TB test, and Marilyn would take him over there. Catherine expected a smooth transition:

When we visited there today your Dad seemed to have a good time chatting up the old ladies, and they gave him ice cream after lunch, so he was a happy camper. I think this transition is going to be harder on me than on him.

## CONTEXT

The United States is sometimes described as having not one, but fifty different health-care systems. It might be more accurate to describe it as a “blended” health-care system, in which federal and state governments interact with the private market. Our residential care system includes very few facilities that are operated directly by the government.

This was not the case prior to 1935 (when Dad was 11 years old). Almshouses, largely populated with older adults, were funded and operated by local governments. Charitable groups, eager to ensure that their own elders never had to live in these wretched facilities, established small private facilities that were more like what we now know as group homes – small residences with 16 to 20 older adults. Although the quality of almshouses was improving, the federal government sought to encourage private facilities, and in the 1920s it prohibited payment of Old Age Assistance (OAA) to residents of public almshouses. These payments were available to residents of private homes, however; and many of these added nursing staff and call themselves “a private home with infirmary.” The 1935 Social Security Act continued this tradition, and a private nursing-home industry grew up with minimal government regulation (Schell). With the 1965 advent of Medicare and Medicaid funding, the industry grew exponentially.

But there were growing concerns about the quality of care provided by these nursing homes, and in 1987, Title IV of the Omnibus Budget Reconciliation Act (OBRA) instituted sweeping reforms. In order to receive payments from Medicare or Medicaid, nursing homes were required to meet federal requirements, including:

- uniform certification standards, a revised inspection process, and expanded sanctions for noncompliance;
- regular evaluation of residents and formal care plans;
- staffing levels for nursing services, social services, rehabilitation, pharmaceutical care, dietary services, and a full-time social worker; and
- competency evaluation and a minimum of 75 hours of training for nursing aides.

In addition, the law established rights of nursing-home residents to:

- remain in the nursing home (except in cases of non-payment, dangerous behaviors, or significant changes in medical condition);
- be free from abuse, mistreatment, and neglect;
- choose a personal physician and access medical records;
- be free of unnecessary physical and chemical restraints;
- manage their own financial matters; and
- receive visitors and access a private telephone. (Wiener et al.)

The subsequent title of OBRA addressed energy regulations, and a comparison of the two led some to observe that, in the United States, nursing homes are regulated more strictly than nuclear power plants (Franklin). Later those regulations were expanded and clarified by additional legislation, which set the stage for assisted-living facilities.

## **THE RISE OF ASSISTED LIVING FACILITIES**

In the 1990s, growing concern about the over-medicalization (and the high cost) of nursing homes led U.S. gerontologists to advocate for the expansion of community-based alternatives to establish a “continuum of care.” Then along came assisted-living facilities. These alternatives to nursing homes expanded rapidly during the 1990s, particularly in the West, where they were widely touted as the “new model of long-term care” that “dazzled with its promise” (Hawes et al. 1; Wilson 18). Indeed, the California Advocates for Nursing Home Reform (CANHR) reported that “over the past twenty years, residential care/assisted living has become the fastest growing component of long-term care” (CANHR 3).

Assisted-living facilities were (at least in theory) “designed to accommodate individual residents’ changing needs and preferences; designed to maximize residents’ dignity, autonomy, privacy, independence, and safety; and designed to encourage family and community involvement” (Assisted Living Quality Coalition 4). They cater to “private pay” residents, who do not rely on the federal subsidies available through Medicare and Medicaid; therefore, they are not subject to federal regulations associated with those subsidies. Instead, they are defined, licensed, and regulated by the states.

In 2014 the Centers for Disease Control and Prevention (CDC) reported that there were 15,600 nursing homes in the United States, of which most (70 per cent) were owned and operated by for-profit organizations, 24 per cent by non-profits, and 6 per cent by government and other entities. At the same time, there were about 30,200 assisted-living and similar residential communities, housing one million residents. Among them, 82 per cent were for-profit, 17 per

cent non-profit, and one per cent government and other entities (CDC 2015). Whereas 16 per cent of nursing homes were located in the West, 42 per cent of residential care communities were located there; and the vast majority of both were located in major metropolitan areas. A minority of both nursing homes (15 per cent) and residential-care facilities (12 per cent) operated separate dementia-care units.

In the absence of nationally agreed upon definitions and standards for assisted-living facilities, conditions vary. California, with more assisted-living facilities (or RCFEs) than any other state, uses this definition: “a voluntarily chosen housing arrangement where residents are 60 years of age or older and where varying levels of care and supervision are provided, as agreed to at the time of admission or as determined at subsequent times of reappraisal.” (U.S. Department of Health & Human Services, 1998)

In 2013 there were 7,500 licensed RCFEs in California, serving over 174,000 people. The vast majority (over 90 per cent) were owned and operated for profit, and most had six or fewer beds (CANHR). The licensing regulations for these facilities are 28 pages long; Mississippi’s, by contrast, take only four pages. They specifically prohibit admission of someone with “active communicable tuberculosis” (hence the dreaded TB test). Facilities are allowed to issue 30-day eviction notices for nonpayment or failure to comply with facility policies, or if the resident has a need that was not previously identified. Further, assessment is required to address functional capacity, mental condition, and social factors. Admission of persons with dementia requires annual medical assessment, adequate supervision, enhanced physical-plant safety requirements, and an appropriate activity program.

The state also specifies training requirements for administrators and direct service staff. Those who provide direct care with Activities of Daily Living must receive at least 40 hours of documented training in their first month and 20 hours per year thereafter. Staff who help with administration of medication must complete 10 hours of initial training in smaller facilities and 24 hours in those with 16 or more residents. These staff are required to complete eight hours of annual training in subsequent years (NCAL State Regulatory Review). As a comparison, in California, nail technicians are required to complete 400 hours of training before they are licensed (*California Board of Cosmetology Licensing Requirements*).

## MOVING DAY

Dad moved into a small RCFE called “Casa de la Felicidad,” on 11 January 2012. Tai, the owner of the facility, encouraged Catherine to tell Dad an acceptable fiction that would explain the move:

I'll tell your Dad that we have to have the house tented for termites, so we all have to vacate for a few days. Marilyn will tell him he can't stay with her because her mother is visiting. And I'll tell him that I will be taking the cats with me to stay at a friend's house. That's our story! If you talk with your Dad before he moves, please keep it in mind. This weekend we are doing some heart-wrenching "lasts," though of course he doesn't know that.

Tai also advised her to stay away for a couple of weeks, so Dad could adjust. Apparently, this is fairly common advice in "the industry." After moving day, Catherine wrote:

Amanda, it was more difficult than I anticipated. He hated the place, disliked the people, and resented having no choice in the matter, even though we said it was only for a few days "while the house is tented for termites." Seemed to me there were more high-functioning residents there, and more staff, when we visited before. I came away thinking I'd made a huge mistake ... I couldn't stand for your Dad to be miserable there, and if that's what happens, we'll have to make some changes.

Now I must enter withdrawal. Your Dad anchored my life, the last few years took it over completely. Now I am adrift, with no clear idea who I am any more. Close friends have moved away, or distanced themselves in other ways. For so long I have been mainly the dispenser of pills, the provider of meals, the meeter of needs, the foil to your Dad's remaining and repetitive attempts at repartee. What now? An empty house, a sore heart, only kitties to feed, no one to hold me while I weep. I'll get through it, but please keep me in your thoughts tonight.

A few days later, things were "so far, so good." Marilyn visited Dad on weekdays and he seemed to benefit from the continuity. The manager of the facility said it was alright for me to visit, but not Catherine. Less than two weeks after Dad moved in, Catherine wrote:

Amanda, this rollercoaster is driving me crazy. Every day I get a call from Tai about your Dad's bad behavior, then later I get a call from Marilyn about what a good day he had! Tonight I got a second call from Tai, and he does want your Dad out of Casa de la Felicidad, because he frightens the staff. Tai gave me the name and number of a relocation specialist who found an appropriate place for the last resident they kicked out (the one whose room your Dad was waiting for). Her name is Betsy Sheehan, and her phone number is ... Tai encouraged me to involve her to make sure we get the best fit for your Dad, which might or might not be Munio. I called her number and left a message.

Tai said Dad had removed his leather belt and threatened the staff with it. Catherine explained that:



Apparently he had fallen asleep in the living room, and they were trying to get him to get up and go to bed. They locked themselves in the kitchen and called the owner, who came and calmed your Dad down, then called me.

I imagine Dad was growling. He used to slowly take off his belt and growl at us when we were kids. But he never, ever hit us. Dad was a small, wiry man. But the aids were smaller, softer, Latina women. He could have scared them. And, given Marilyn's calming presence, it's entirely possible that he had a good day while she was there and behaved badly when she was not. My response to Catherine:

Yes, it does sound maddening. Bottom line is they want him out ... I'd like to know what Betsy Sheehan's background is, and who pays her. Apart from that I guess ideas are welcome – confusion's not. We have plenty of that! It'll work out – and I do think we'll be able to get Dad settled and reasonably happy eventually... he might outlive us all! See you Saturday.

And so it went. Tai said Dad was trying to jump over the fence and escape. Marilyn said he was just inspecting the fence and didn't try to go over it. She saw Dad as a happy camper and Tai saw him as "combative." Tai nagged Catherine daily. He wanted Dad on an anti-psychotic called Seroquel, but Catherine learned it was contra-indicated for people with dementia. She hated to see him drugged, and said, "Here we go, 'chemical restraint.'" But soon he was on Seroquel and Tai was urging increased dosages. I called the long-term care ombudsman, who told me dad had a right to 30 days' notice. Then I called Betsy Sheehan, and reported back to Catherine:

She refused to give me references or a list of facilities she uses and has no training in elder care. She's a marketing person who gets a finder's fee [The receiving facility pays her half of one month's rent, about \$ 4,500.] if she places him, regardless of how long he stays there ...

Against all advice, Catherine began to consider taking Dad back home. She spent an hour on the phone with Betsy and found her "very helpful." Betsy explained that Tai can "get emotional at times." Ultimately, Tai threatened to call 911, and told Catherine that would make Dad "very hard to place." Betsy suggested a facility called Crescent Lodge, which was over an hour's drive from home during those rare times when there was no traffic. I wondered whether Tai would get a kickback if she placed him there. I made an appointment with Rachelle (whom Sharon had recommended), and she agreed to go to Casa de la Felicidad and do an assessment of Dad. I called the Veterans' Administration's

Extended Care Liaison to see what help they could give (none). Within hours, I received an email from Catherine:

Subject: I'm picking up your Dad tomorrow.

Tai called tonight to say your Dad was threatening the resident in the next room. I can't take any more of this so I'm going to go get him tomorrow.

## HOME

So Catherine took Dad home. She engaged his night caregiver to stay with him. The next morning, she wrote:

Your Dad seemed fine when I brought him home, we had a pleasant evening. But then in the middle of the night he became violent, and threatened both me and the caregiver with anything he could find to use for a weapon. At one point he tried to strangle me. [He also threw an Adirondack chair at her and was roving through the house looking for weapons when she called the sheriff.] It was like he was in a trance. He has never offered me violence before. I had to call 911, and now he's in the ICU at Dominican Hospital for safety.

I sent a message to my brother, "All hell has officially broken loose." I spent the rest of the day on the phone. Dad was in physical restraints in the Intensive Care Unit. They had put him on Haldol and expected to move him to the Medical-Surgery Ward. I jotted phone numbers, suggestions, questions and misspelled drug names in my journal:

5:30: Esther – napped a couple of hours, switched from Seraquel to Zyprex, olanzapine ... Catherine – Dad's still in restraints ... Seraquil? Geodon? Treatment plan? Zyprexa? No medical issue. Unstable. Restraints. Social worker: Do not let them discharge him to you. Must refer to psych. When will he be stable? Fran 6:15: Pleasant in AM, restraints in PM. Came in as observation patient. Social Worker: Medicare may refuse to pay. Look at RCF not SNF. Family must do that. How long? 24 hours. He has to be stable. Talk with nurse @ reversibility. 2nd opinion. Delirium, temporary condition, Infection?? On Diproxin now. Dr. Wilson: Great this morning. Medicine takes the edge off but can't help with the real challenges. Needs 24 hr. care. Meds help stay calm and not wander. Will get harder and harder until something else takes him.

The journal also has a long list of facilities and a note: "Rachelle at Munio says no. He's too fit." And a quote from Betsy Sheehan, "I feel your pain." I called the hospital before getting on the flight from Salt Lake to San Jose: 10AM: He's in critical care, nurses station "waiting for bed to open" – Urinary

infection – urinalysis fine, clear, Order says to be discharged today. Dr. Christianson on duty, call Ella in 45 minutes.

An email arrived from Catherine:

Subject: Your Dad is going to Crescent Lodge.

He'll be going there in his pajamas. I think I'll take a suitcase over to the hospital in the morning, and see if the social worker can make sure it goes with him.

While I was in the air, Dad was transported to Crescent Lodge. I arrived at the facility less than an hour after he did. Dad was in a large private room with a small twin bed and a separate bathroom with sink and toilet; pale and tired, but he wasn't in pajamas. I sat down at the edge of the bed, pulled off his socks, and rubbed his feet the way he used to rub mine while I drifted off to sleep. After I left, an aide called Catherine to say Dad had fallen in the hall and they wanted to know if they should take him to the emergency room. She said, "No." The next morning, I asked the administrator to please not bother Catherine. She said they had to call someone, so I gave them my cell number. For the next few days I got a call from a different staff person every night around 10pm. Either Dad was combative and they wanted permission to sedate him or he had fallen and they wanted to know whether they should take him to the Emergency Room.

The facility referred us to a doctor who served other residents, Ivanna Yeltsin. I sent Catherine an update:

Subject: Dad

It's hard to say how dad is. In a lucid moment yesterday he was talking about suicide and worrying about the tax bill when he died. Then he wanted to ask Helen [his deceased first wife] something and was distracted by ants he saw crawling across the carpet in his room. He complained of pain in his left knee, but didn't seem to remember the scrape he got on his elbow. He tired easily, but couldn't settle. Up and down, changing chairs (which was difficult because he has a hard time sitting down). He's weaker than he was on Saturday... It's hard to say what is meds, what is the challenge of adjusting to a new setting and what is grief and anger.

He's surrounded by people he doesn't know, some of whom act bizarrely. Dad tries to make conversation but most of them don't respond ... So he retreats into silence. There's a woman who shouts "honey!" whenever she spots a staff person. There's another with scary facial twitches who tries to talk but can't be understood. There's a Vietnam veteran named Jerry who talks a lot and sometimes makes sense. It's tempting to interact with him because he seems capable, but he doesn't always respond. I think a couple of the women have potential. One was throwing a bean bag from her chair during afternoon activity.

The staff vary. Roland, the guy from the Phillipines, is my favorite. He has a nice smile, seems kind and is alert to the needs of residents. There's a lovely black woman who likes to dance, but she seems to be assigned to only one or two of the residents. She doesn't circulate. There's Rico, a big guy with a grim expression. Chris is nice. Julie took care of Dad his first night, but I never saw her again. She's Asian and has a strong accent but a good vibe. They wear gloves when they serve food or touch the residents.

I ate two meals there today – the food is high on carbs, bland, low on fiber [hence the near-universal use of stool softeners] and (I imagine) vitamins. Dad enjoyed the ice cream dessert and the first night ate four servings. I bought him some fruit salads [at a nearby grocery] which he seemed to enjoy.

In my journal, I wrote some quotes from Dad:

*I'm in the middle of the jungle. It's so loud and there's no real leader.  
I need to get out of here pretty soon.*

The administrator asked me to keep my visits short because Dad became disruptive after I left. She told Catherine to stay away for at least two weeks to give Dad a chance to “connect to the place without too many reminders of home.” (Later, Catherine put a stuffed cat and some family photos in his room, but he didn't seem to notice.) I found it wrenching to leave him there. I'd linger, waiting for him to fall asleep after lunch. Then I'd sneak out, so discomboluted that I forgot the code to unlock the exit and had to wait for a staff person to come let me out. While I stood staring at the wall, I told myself that Alzheimer's was contagious.

I didn't like Crescent Lodge. It didn't smell, but it was loud, especially when the activities director was using her microphone. The social spaces were small and crowded, and the staff were stressed out. Apart from a front lawn that residents couldn't access, there was no grass, just a concrete patio with a few container plants. Most of the residents were more demented and/or more disabled than Dad. Each day when I left Crescent Lodge, I went searching for a better option. Maple Creek had more space and less debilitated residents. It was quiet, but not better enough to merit the stress of moving. I wrote Catherine about my visit to Bayside Villa, where a friend of Marilyn's had stayed:

There I met Russ – a friend of Steve's. Steve is the owner at Crescent Lodge. I saw him there twice. The first time he explained to me that I should not hope for my dad to improve because he had Alzheimer's. The second time he walked past me as if I weren't there. There's a lot of that. I guess it's what people do when [they] have nothing in common but decrepitude. Bayside Villa was pretty awful, which made it easier to go back to Crescent Lodge and see Dad.

This is a strange industry, in part because those who work in it refer to it as “the industry.” Russ and Steve both run what look to be mid-tier, old-style facilities. They face heavy competition from [newer] places like Maple Creek, which charges about the same rates. Of course, Russ and Steve have vacancies – Maple Creek doesn’t. At least not now. So no wonder the old guys are nervous.

As I searched, I learned more about the industry. For instance, the base rate of \$9,000 per month is not the only charge. You pay extra for continence and dementia care, for transportation, for medical equipment, for oxygen, for special dietary needs, and so on. You never know what the bill might come to in any given month, so you’d better keep a credit card handy. But Dad adjusted quickly. As I told Catherine:

On Saturday I would have said Dad did not belong at Crescent Lodge. When I saw him Wednesday I would have said he was incapable of living outside a facility of this kind. Now, he seems to be settling in – adjusting his behavior to its ambience. This is clearly easier for the staff, and probably for him, as well. He’s safely warehoused and, as Bill [the owner] explained, there’s not a lot to hope for.

I puzzled over the lack of a care plan. I wondered what it would take to get Dad a morning newspaper, whether he could take care of a few plants. I talked with a nurse who attributed Dad’s agitation to my presence. Seems they had “another guy” who showed agitation until they reduced family visits. I explained that Dad had no family visits over the weekend, and yet last night he was more agitated than ever. I asked why Dad was taking Zyprexa, which is contra-indicated because it causes elevated risk of stroke. She said, “A lot of doctors don’t like to prescribe Zyprexa,” and suggested that Dr. Yeltsin might wean Dad off it. Then the driver arrived to transport Dad to Dr. Yeltsin’s office. When I called to ask the doctor to begin weaning Dad off the Zyprexa, the woman who answered the phone said the doctor had just left to go to Crescent Lodge to go see Dad. I said that was unfortunate because Dad had just left Crescent Lodge to go see her. The woman came back to say Dr. Yeltsin was actually in the exam room with Dad.

When I finally got the doctor on the phone, her first question was “Why is he taking Lithium? I never prescribed Lithium!” I had no idea, but I gathered she was concerned about medication interaction with the Lorazepam. She wanted him to go on Depokote and just take Zyprexa at bed time and as needed. She said Atarane was not so good. For some reason I wrote “benzodiazapene” next to it in my journal. She asked about blood work, and I told her the hospital did check for Urinary Tract Infection (UTI) and might have looked for other things but I didn’t know. She agreed to “wean him down” off Zyprexa and put him

on a mood stabilizer. She gave the name, but I couldn't understand her accent very well.

During the following two weeks, I took charge of Dad's care, so Catherine could get some rest. I spent as much time with him as I could, and when I wasn't in the facility I searched for alternatives, studied up on pharmacology, and attempted to orchestrate the various providers. Marilyn was present most weekdays, charming staff and administrators and calming Dad. Most of the staff thought we were sisters. Here are some notes from my journal:

- Me: "How are you?" Dad: "Hoping to pass inspection."
- This morning Marilyn said when she got there Dad was unresponsive. She could not wake him up. Staff said he was agitated and they gave him something. He didn't wake up at all. Liz [nurse] called doctor, said would discontinue. It's what he took at 8 AM.
- Dad: "The phone's unsatisfactory but it'll do. It calls some places, but not home. 1-2-3-4 there's quite a few people here. They're all talking. How can they find things to talk about?"
- Last night he was up when Marilyn called. He was alert, lucid.
- Julie [aide]: very good today. Last night not too bad – 12–4 slept up @ 5 picking up things from the floor
- Dad: "I'm going to bend their rules and go up to the mountains."
- Anna [Doctor's Admin Person] will call back when she finds medical records. No lab results just CBC [complete blood count].
- Dad: "I'm anxious to see Hawaii. It's so cold today. I want a ticket to Honolulu."
- Called Anna and told her about bloodwork and kidney stones. Can we have a conference call?
- Dad: "Left or right, there's no choice. People here in California are used to choice."
- Marilyn said a visiting nurse came in the other day and noticed red spots on his tummy. His left eye is red and legs are swollen. She says swelling is a side effect of the medications and wants him on a salt-free diet. Ointment is needed for dry skin and wounds, tear drops, and change laundry soap. She ordered a walker. Depakote, 30 mg and at lunch, Zyprexa 30 PRN. Took him off some because he was unresponsive. She'll be back Wednesday.
- Dad: "Just saw a cat go out the door. Cat food. Got to get some good cat food."
- Can't get Dad's shoes on because his feet are swollen.
- They took his belt away. Catherine ordered some elastic waist jeans.
- Lynne called. Walker will be delivered, but Medicare only pays 80 per cent. Gave my credit card for remaining balance, about \$20.
- Can Dad have a private phone? What would it cost?
- Dad, looking at his reflection: "I have an animal in the mirror."

- Wednesday: Lynne called and asked me to call the doctor. Dad is unusually sleepy. My sense is she needs help and doctor is refusing. She says we'll find a quiet phone near room 19.
- Dad: "You've got to dream up things to do with boats."

I grew increasingly frustrated with Dr. Yeltsin, and one of my children suggested I post a review on Yelp. A quotation from W.E.B. DuBois came to mind, "We must complain. Yes, plain, blunt complaint, ceaseless agitation, unfailing exposure of dishonesty and wrong – this is the ancient, unerring way to liberty, and we must follow it" (621). So I gave Yeltsin 2 out of 3 stars and wrote, "I think she's OK face-to-face, but she doesn't return phone calls and doesn't do conference calls." The next day the doctor called Catherine and told her she was "depleted" by my post, and that I had made trouble for her. She would not discuss Dad's care until I took down the post. Betsy Sheehan, the relocation specialist, sent me an email that echoed the threat and accused me of being "an angry woman." "You're damned right I'm angry!" I thought, as I took down the post. My father was dependent on these people, so it was time to suck up and take it. Catherine was furious with me. Her naturopath called to tell me I was giving her unnecessary stress and I needed to be more supportive. I was immediately relieved of responsibility for Dad's care.

I quit worrying about medical records, staff qualifications, and mealtime experiences, and spent time online ordering things for Dad: a monthly fruit basket, a plastic tool kit, puzzles designed for people with dementia, a fuzzy hat, flannel shirts, warm socks. Lucas and I took to visiting Dad once a month on weekends. I'd look around the room, but could never find the gifts I had sent. We would take Dad out for seafood and beer, bring him back late – often with his pants full – and turn him over to staff with a guilty apology. Eventually, Dad forgot how to walk. He still could, but his mind wouldn't tell his legs what to do. So whenever we needed to walk somewhere I held his hands and walked backwards just as Dad did when he taught me to dance. I repeated, "One, two, cha-cha-cha. One, two cha-cha-cha" while other pedestrians veered out of our way. Occasionally, and I sometimes thought surreptitiously, Marilyn would let me know how Dad was doing. She told me, for instance, about the time he was found passed out on the floor with low blood pressure and a slow heartbeat. They sent him alone to the ER, and he didn't know why he was there.

Eventually, Crescent Lodge was sold and the quality of care deteriorated. Dad developed frequent UTIs, and enough was enough. So Catherine moved him to one of the places we had both visited (separately) and liked better, City Square. It was a larger facility, with a locked dementia wing. Dad shared a room with another man, but he seemed to enjoy that and I felt better thinking of him less alone. On Saturdays we ran into other families and exchanged grimaces, but not words. We were all in our own, opaque bubbles bouncing against each

other, but seldom connecting. The place was better, but it was still hard to leave him.

By the time my brother and I took Dad out to celebrate his 90th birthday, he was no longer walking. He had his own wheelchair. The day was sunny and still, so we went to a café on the beach. As usual, Dad had fish and chips, but this time he didn't finish his beer. He just asked to be wheeled out onto the wet sand so he could feed the gulls.

## **DO CHAPTERS HAVE EPILOGUES?**

American enthusiasm for the private market is not entirely unfounded, but even Adam Smith, in *Theory of Moral Sentiments*, acknowledged that some parts of life must be kept safe from market influences. Capitalism can expand the pie. But when it does so at the expense of the vulnerable, we all suffer. The practical challenge for long-term care (as for other sectors in the American economy) is to strike an effective balance, to harness the incredible power of greed and, through appropriate regulation, direct it towards the good of humanity.

In their 2013 report “Residential Care in California: Unsafe, Unregulated, & Unaccountable,” the CANHR attribute the incredible expansion of RCFEs in part to the absence of regulation. They note the increased frailty of residents in these facilities, and argue (as *Frontline* did in its 2013 documentary, “Life and Death in Assisted Living”) that five years ago these elders would have been placed in nursing homes. The CDC’s 2014 long-term care survey partially supports this view. For instance, it reports that a higher proportion of RCFE residents were 85 and over (53 per cent) than those either in nursing homes (42 per cent) or in hospice facilities (47 per cent). But whereas half (50 per cent) of nursing-home residents had Alzheimer’s, only 40 per cent of RCFE residents did so. Likewise, 91 per cent of residents in nursing homes needed assistance with locomotion or walking, compared to 47 per cent in RCFEs (CDC). Perhaps it is more accurate to say that “some” of those in assisted living would have been placed in nursing homes. But the rest might, like Dad, experience significant declines in their functional ability during their time in residence. Certainly, these are among the nation’s most vulnerable.

Our family was among the more privileged of consumers. Like Robert Kane (who recounts his family’s experiences in *It Shouldn’t Be This Way: The Failure of Long-Term Care*), we were well educated and possessed significant financial resources. Yet we struggled to get accurate and useful information to help us make decisions, and our experiences of care were far from ideal. We encountered facilities that were understaffed, and staff who were undertrained and overworked. Despite moments of incredible kindness by some nursing aides, the quality of care we were able to purchase was inadequate. Our experiences



also underscored an observation by the CANHR that “the chemical restraint of RCFE residents knows no bounds. Unlicensed and barely trained aides give out antipsychotic drugs to residents like candy, while often little or nothing is done to respond to the underlying causes of pain, illness, despair and distress” (11).

Clearly, the situation calls for more effective regulation. Highly prescriptive regulations that limit staff initiative and divert resources from caregiving to paperwork can be counterproductive. But stringent regulations that determine the conditions of care such as staffing and funding levels, training requirements, and facility safeguards can support quality (cost-effective) care (Banerjee and Armstrong; Mukamel et al.). CANHR recommends the development of a three-tiered level of care system, with differential requirements based on residents’ degree of disability. They advocate annual inspections, preferably unannounced; vigorous investigation and reporting of complaints; and penalties for violations.

Families need better information as they choose from the array of long-term care options so that they don’t have to rely on marketing personnel, private “relocation specialists,” word of mouth, or sporadic reviews on Yelp and Google. Long-term care ombudsmen need authorization and resources to maintain a registry of complaints and make it publicly available.

Finally, during Dad’s time in residential care the Affordable Care Act passed. Tightly regulated exchanges were set up so that Americans could purchase health insurance and know exactly what they were getting. I wrote in my journal: “We need long-term care exchanges too.”

### Final Visit

Dad hands me a warm rose petal,  
brown around the edges,  
whispers  
*Huh. Soft. Feel that.*

A withered woman asks,  
*Can you open the door for me?*  
But the aide says  
*No. She’s not  
allowed.*

We’ll shuffle  
out  
through a different  
door.

We stop in the maple shade,  
and he  
murmurs  
*Trees, to me, are attractive.*

*Lately, I've been taking  
photos of people.  
I'll photo them  
down  
to nothing.*

The almost spring  
sun warms  
his temple,  
and he tells me

*My end is –  
I'm carrying it, I think.  
I'll unload,  
put something together,  
and close up.*

I don't really understand  
as so often before  
I just write down  
what he's saying.

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# On Not Being Invisible

## Life in a Continuing Care Retirement Community

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*Anne M. Wyatt-Brown*

In the years that I have lived at Roland Park Place (RPP), a Continuing Care Retirement Community (CCRC) in Baltimore, Maryland, I have created hypotheses about how to adjust to a place like this and subsequently been forced by changes beyond my control to discard a good many of my initial theories. From the moment I learned that the average age of residents here was 86, I began to turn to my background in humanistic gerontology to help me adjust to a place that otherwise might have seemed inappropriate for a person who was only 71. After all, the only reason I had moved in was that my 78-year-old husband Bert needed to be here.

As a newcomer, I expected that there would be a period of adjustment followed by developing a sense of belonging. I knew that some changes in my life would then alter my feelings. After all, I assumed that I would have a big adjustment after he died. Besides that inevitability, in time I would grow older and become more infirm. At that point I might have to move into assisted living or health care, a change that would force me to make another adjustment. What I did not expect was that decisions brought about by a few managers at RPP might alter my sense of belonging much sooner than any physical decline.

## BACKGROUND

In order to understand my reactions, it helps to know how I got interested in humanistic gerontology in the first place and why family history encouraged us to select RPP (Wyatt-Brown, "Once").

From the beginning, my interest in gerontology has included a combination of personal and academic concerns. Initially, my experiences with older relatives drew me into the field. First, in 1967, Bert's mother had two strokes when she was living in Sewanee, Tennessee. She loved Sewanee, the home of the University of the South. Sewanee consisted of the college from which her sons

had graduated, as well as an Episcopal seminary, attended by her husband and Bert's two brothers. The town, however, had no medical facilities for people who needed health care. As a result, Bert's older brother, Charlie, decided to move their mother to Houston, Texas, where he was the rector of Palmer Memorial Church.

Charlie and his wife Sheppy placed his mother in a nursing home fairly near their house. They did not consult her; they simply distributed the furniture to the children that had been designated by Mrs. Wyatt-Brown in a previous will, got rid of the dogs, and sold her house. As a consequence of not being consulted, Bert's mother experienced some moments of depression. She missed her dogs and was horrified when a photograph we had sent her contained a picture of a piece of furniture that had belonged to her. I thought Bert's mother needed therapy to help her deal with the situation, but her doctor put her on medication and hoped for the best. She died nine years later in December 1976.

I learned from her unhappiness two related things. First, it can be dangerous to one's sense of autonomy to try to age in place when a decline in one's health makes that impossible. Second, if older people do not plan for the future, their children will be forced to make life-changing decisions for them. Still, when Mrs. Wyatt-Brown died in 1976, I was only 37, which is much too young to think about planning for the end of one's life.

Although I was too young to worry about my aging, David Van Tassel, Bert's colleague in the history department at Case Western Reserve University (known to us as Reserve), was aware of a dramatic increase in the number of older people in the United States. As a result, he thought it would be important to encourage humanities scholars to study gerontology. Therefore, in 1975, Van Tassel organized a local conference on Human Values and Aging. Because the meetings took place at Reserve, across the street from where I was teaching at the Cleveland Institute of Art, I was able to attend many of the presentations.

David invited scholars and authors who themselves were growing older and asked them to write about their thoughts on the subject of aging. Although some of them had not yet written about the topic, they gave impressive papers. The speakers included Leon Edel, the biographer of Henry James; Leslie Fiedler, a well-known literary critic; and Erik Erikson, a psychoanalyst who had written about stages of life but had not yet emphasized aging. I found the conference stimulating and informative. I was also fascinated by the work of a British historian, Peter Laslett, who reported that in earlier centuries, English rural families lived near each other, but the young members did not take their elders into their houses. Nonetheless, some years later he argued that the family members maintained close emotional ties despite living in separate dwellings. These essays were later published in Van Tassel's 1979 anthology *Aging, Death and the Completion of Being*.

Then in 1981, Van Tassel ran a month-long NEH summer institute at Reserve, called Old Age in History and Literature, hoping to attract faculty members in humanities to the field. My interest in aging had increased because I had discovered the late-life novels of Barbara Pym, a British novelist who had a 17-year hiatus in her publishing career. As a result, I welcomed the chance to become an NEH fellow for that month. Bert said that it was like sending me to day camp. I came back each night full of enthusiasm for the ideas to which I was being exposed.

Two years later, Bert and I moved to the University of Florida (UF). Thanks to Hal Stahmer, Bert's friend from his time at King's College, Cambridge, who had subsequently become a professor of religion at UF, I attended my first GSA conference in 1983 on crutches, having recently shattered my patella. I was allowed to create a poster rather than give a paper. Having no idea what that entailed, I took the paper I had written and posted all six pages in the spot I was assigned. There I met other scholars interested in the humanities and aging so we were able to organize a panel for the following year's meeting. In retrospect, I am grateful that people were helpful to me rather than contemptuous of my inexperience in the world of posters.

Upon reflection, however, I think it's really not surprising that I found gerontology to be a compatible subject. In many ways my childhood had prepared me for my midlife interest. I had grown up in a large extended family, so I had been exposed to several generations of aging people whose choices changed over time. My father's mother and his aunts had stayed in their house in Bolton Hill, Baltimore, using household help as their health declined. This grandmother was bedridden; she lived on the second floor while her sisters and Miss Sadie Poe lived in the rooms on the first floor. The large house allowed the women to create a community but to retire to privacy whenever they so desired. We visited Granny and her sisters every Sunday after church, and Dad's brothers and sisters visited frequently as well. I was too young to know if loneliness was a factor for these elderly women, but few of them complained about their lot. When Granny died at the age of 82 in 1949, hers was the first funeral that I had ever attended.

In the next generation, Dad's brothers and sisters made different choices. First, some moved into the Wyman Court Apartments on Beech Street, quite close to our house in Guilford. We liked to think that Dad's siblings took over the building. When their health declined or dementia set in, they moved to Keswick Multi-Care Center, a few blocks away. When my Uncle Fendall died at Keswick, his widow, Aunt Jane, moved into Broadmead, a CCRC in Cockeysville. She was given a scooter, which allowed her to go anywhere she wanted to in the building. She felt emancipated. Another family widow, Jo, moved into Blakehurst, a Towson retirement community, when her husband died. Both

women enjoyed life once they no longer had to take care of sometimes difficult husbands.

Mother's family was much smaller. Her mother, my great-aunt Virginia, and my Aunt Anne lived first on Preston Street in a second-floor apartment. Then in the 1950s, Aunt Anne inherited some money from her Uncle Ken and bought a house on Rugby Road in Guilford right around the corner from our house on Warrenton Road. As a result, I could hop over the neighbor's fence to visit them. I loved spending time with them because I was named for Grandmother and Aunt Anne, and they made a fuss over me.

Grandmother had a heart attack at the age of 76, and while she was not bedridden she didn't leave the house after that event. The family hired a companion, whose company Grandmother did not like. At the end of her life, only Mother and my uncle visited her; we children were told that company would upset her. Great-aunt Virginia had died much earlier, leaving behind a closetful of dresses that she had never worn, my mother reported scornfully. Aunt Anne had a stroke many years after Grandmother's death that made her housebound for ten years. My brother Luke and his wife, Nancy, were in charge of her when she was bedridden toward the end of her life.

As my parents aged, we discovered that they had different ideas about how to spend their declining years. My mother, like many other people, wanted to stay in her house. Many of their older friends had aged in place, and Mother had followed their stories very closely. She had never lived in a community growing up. Her father had died when she was in eleventh grade after years of being too ill to work. As a result of the drain on their finances, Mother left school without a diploma and never went to college, where dorm life might have prepared her for a community existence. My father, however, wanted to make sure that she would be taken care of after his death. He decided that they would move into RPP, which at that point was very new.

Therefore, in December 1986, my parents called a family meeting to announce that they would be moving into RPP in the fall of 1987. I'm assuming that Dad decided on that place because it was so close to the house where they had been living for about 50 years. Nonetheless, the move was traumatic. Mother wanted to keep an eye on every item when it was packed, which was of course impossible. Dad, on the other hand, was indifferent to most things once he found a good home for his books. Bert and I took many of them, an act that relieved his mind.

Once they moved in, Mother had a much more difficult time than Dad did. Besides lacking community experience, she had glaucoma, a detached retina that had not healed properly, and a cataract in the one good eye. Her doctors didn't want to remove her cataract, because if the operation was unsuccessful, she would be blind. What they didn't realize was how her inadequate vision was making it nearly impossible for her to adjust to life at RPP. Unlike many resi-



dents, Mother did not tell people that she couldn't see. As a result, she feared that she might fail to speak to a friend if she didn't recognize her when walking in the building.

To avoid being inadvertently rude, Mother spent a good deal of time in the apartment, except when a family member came to dinner. In contrast, Dad kept meeting people he hadn't seen since school days. He continued to be active in his law firm as a consultant and had dinner with many people at RPP. The ease with which he found dinner companions was not surprising. There are many more women than men in CCRCs, so new men are snapped up by observant women. My sister, Susan, and I would talk to the head nurse about Mother's isolation, but the nurse said that some people could not be helped. Sadly, my relatively well-adjusted father died in March 1988, whereas Mother lived alone in the apartment until she died in 1993.

## EARLY DAYS AT ROLAND PARK PLACE

What the complicated family history taught me was that one of the most difficult choices of later life can be deciding where to live. My guess is that when one is faced with the necessity of making a change, even gerontologists may not necessarily consult the current literature, especially if circumstances dictate a quick move. Fortunately, in 2015, Stephen Golant composed a comprehensive study of the possible places that an older person could select, *Aging in the Right Place*. He points out that it is almost impossible to avoid messages on television, on the Internet, in books about later life, and in newspapers that insist that the ideal is to age in place (63). In contrast, he discusses the advantages and problems that can emerge when people try to stay in their dwellings. Instead of selecting one kind of possible place, he covers as many alternatives as now exist. Each alternative has advantages and disadvantages, so Golant suggests which kind of place might appeal to different kinds of personalities. His book is comprehensive and helpful, but unfortunately it appeared too late for us to consult it.

As I wrote in the first essay in *The Big Move* ("A Wife's Life"), my account of my early life at RPP, Baltimore had the worst snowstorm in its history in 2010. We decided to move into RPP because it was in the city and the place we knew best. Initially the adjustment was not easy for me, but after a relatively short time both Bert and I felt at home. I had worried about how I would feel once Bert died, but by the time that happened I had made many friends and had also made a new life for myself largely centered around the Fitness Center. Moreover, residents and staff were extremely kind to me after his death, which made me glad that I had decided to stay at RPP. I thought that

my adjustment was complete until the time when my health would begin to deteriorate.

For several years, things continued to be relatively easy for me. Like many widows, I was very busy after Bert's death in November 2012. For one thing, he had completed a book, *A Warring Nation*, just before he died. It was up to me and my sister Susan, who had helped him before his death to answer questions posed by the editor, to see the book through to press. Luckily, Bert and Susan had worked hard to answer as many of the editor's questions as possible. Then, once Bert died, the number of unanswered questions was relatively small, and many friends helped in ways that I acknowledged in an addendum to the acknowledgments. The book was published by the University of Virginia Press early in 2014.

## **A MAJOR CHANGE AT ROLAND PARK PLACE**

In 2014, a change occurred that was a mixture of positive and negative. It had to do with Stewart and Valencio, who had been running the Fitness Center since we had moved in. As I said earlier, taking land and swimming classes at the Fitness Center of RPP and hiring Stewart and Valencio as personal trainers had given me a sense of belonging. Then on May 15, 2014, Stewart and Valencio won the Maryland Department of Aging's 7th Annual Governor's Leadership in Aging Awards. They invited me to attend the meeting because I was active in the Fitness Center. I was delighted by their recognition because both men were doing a fine job working with the residents.

That positive event was later overshadowed by a more complicated one. To our surprise, Stewart announced a career change. After many years at RPP, in 2014 he decided to start working for a degree as an assistant physical therapist. He cut back his hours at RPP dramatically but planned to continue to work part time until the demands of the program made it impossible for him to continue. He told his boss, one of the managers, that he probably would be leaving for good sometime in the middle of 2015.

In many ways Stewart's decision to further his education had been unexpected. Valencio had been working on a PhD in music education, and we all thought that when he completed his degree, he would leave RPP. Instead, he took over many of the classes that Stewart had taught. As a result, I had the pleasure of taking his land classes, as well as the swimming classes that he had taught for eight years. We all appreciated his willingness to take on extra work, and I enjoyed his engaging teaching style.

## PROBLEMS AT ROLAND PARK PLACE

Unfortunately in 2015, the situation at RPP began to deteriorate. What really caused trouble was that the manager had not tried to find a replacement for Stewart. Therefore, when he announced that he would no longer be able to stay at RPP, she had hired no one to teach his classes. Moreover, the manager made an unexpected change in the structure of the Fitness Center at that time. Both Stewart and Valencio had assumed that Valencio would take over Stewart's job of being responsible for running the Center once Stewart left for good. Instead, the manager decided to interview candidates herself, and she also informed Valencio that he would not inherit Stewart's role. That decision upset Valencio as well as those of us who knew how hard he had been working for many months to keep the programs effective. Not only had he taught most of the classes, but also, when the swimming pool needed to be repainted in July 2014, he had done the work himself to spare RPP from the expense of hiring the pool company instead.

At a meeting with the Fitness Committee, to which I had been invited, Valencio told us that he thought not having one person in charge would interfere with the smooth running of the Center. He was, of course, correct. Unfortunately, the manager ignored what he said. To make matters worse, she insisted on hiring a man with little experience with older people, instead of a woman whom Valencio preferred. Once the new man arrived, the manager kept having private meetings with him, during which, according to him, she encouraged him to think that he would ultimately get to run things.

Not surprisingly, Valencio realized that he had no future at RPP. His phone calls to the manager were not returned, and the new employee usually said he was too busy to meet with him. Two months later, Valencio tendered his resignation, and we had a farewell party for him. The manager promptly hired the woman that Valencio had wanted to hire in the first place, and the two newcomers tried to run the Center without much help from the manager, who supposedly was supervising them. The manager had an ill mother, who lived in Florida, a situation that made it difficult for her to observe what was going on in the Fitness Center.

When I looked over my entries in my calendar, I discovered that the two new employees worked together at RPP for only seven months. At the time their stay seemed endless, largely because we had no idea when, if ever, the authorities would intervene. It seemed to us that no one cared what we thought, and as a result we felt very discouraged. In consequence, my emotions began to fluctuate as I responded to changing circumstances, just like those of Olive Kitteridge, the eponymous protagonist of Elizabeth Strout's 2008 novel.

While things were in flux, I came upon an unusual article in *Aging Today*. Most recent newspaper and magazine articles on aging assume that staying

in one's house is the very best approach to living the last days of one's life. In contrast, the article by Peggy Brick was titled "The Case for Aging in Community, *Not* in Place." Brick insists that if one has enough money, aging at a CCRC is preferable to aging in place, provided that the CCRC is a Quaker establishment.

Quaker CCRCs, Brick notes, do not hire activity directors for people in Independent Living. My friends and I were well aware that Broadmead, the Quaker place outside of Baltimore where my Aunt Jane had lived, allowed the residents to run things for themselves. We were also aware that Broadmead had far fewer trips than we did because we have Marie, a remarkable Independent Event Planning Coordinator, and Jennifer, her assistant, who organize our many outings. None of us has the time or the knowledge necessary to plan as many trips as Marie does. We are not against hiring staff to organize things for us; we just hope they will be competent and care about our wellbeing.

Some time in January 2016, while we were trying desperately to adjust to the newcomers running the Fitness Center, I learned that a resident who had only arrived the previous March was about to move out. I heard, second hand from many residents, some of her reasons for leaving, but I decided that I needed to talk to her myself. Like most of us, I was upset that she was leaving largely because the upheaval in the Fitness Center had made me feel less at home. As it turned out, her reasons were different from what mine would have been. Among other things, she could not sell her house, which made the move overly expensive for her. Moreover, she had lived in a supportive neighborhood, with neighbors whose company she really enjoyed. She had complaints, some of which I agreed with. But then in passing she indicated that she was somewhat uncomfortable in the presence of people in wheelchairs, a sight that of course one cannot avoid in any CCRC. After I heard her complaint, I realized that her decision didn't make me feel less at home. Of course, some people are unlikely to adjust to life in a place like ours. After all, as Golant has said, some people find that their friendships in a CCRC are more superficial than prior relations were. Moreover, the fit residents often avoid mixing with those who are frail because they "find it easier and less stressful to be more active and fully engaged" (329–30).

At the end of March and in early April, things began to deteriorate in the Fitness Center. The male employee who had taken over my personal training from Valencio showed up late many times. When I learned that his wife was having a fourth child, I realized that a new baby would make it even more difficult for him to show up on time for my appointments. I decided to hire Glenn, a personal trainer whom I had seen working with Margaret, a resident who has dementia. I was impressed by his kindness to her. When I told my RPP trainer that I was going to shift from him to Glenn, he asked me to send him an email explaining why I was making the change. I wrote him a long email in which I

explained all the problems that working with him entailed and sent a copy to Katherine, who was chair of the Fitness Committee. She asked me to send my message on to Terry Snyder, who is the CEO of RPP.

At first, nothing happened. Then, a short time later when I flew back from Boston where I had been attending a conference, I learned that Terry and Tracy, the head of IT, had asked several residents to explain to them why they supposedly had spoken disrespectfully about the two newcomers who were working in the Fitness Center. The only reason that I was not interviewed was that I had been out of town and therefore had not answered the phone call. Most of the people who had been asked to meet with Terry and Tracy had no idea who might have said mean things about the two newer employees. In fact, I hadn't even heard many complaints about the woman employee. She was working as hard as she could to make the program work. As for the man, whenever I had a complaint, I spoke to him directly.

A month later in early May, the male employee who had taken time off to help with his new baby returned to work. That day, to his surprise, he was fired. I happened to be using the recumbent bike near his office when two men appeared in the Center to escort him out of the building. I was shocked by the speed with which this all happened. Even though I had complaints about his behavior, I thought to escort him out as if he were some sort of criminal was unnecessary. I actually felt sorry for him. Fortunately, the situation did not stay in limbo very long. Terry announced that they had hired a fitness company to take over the running of the Center. A substitute person began teaching some of the classes, and by June 1, a permanent person, Alex, had been put in charge. The woman who had been working in the Center along with the man who was fired stayed until July 15, when she left for good.

Once the change had been announced and new employees began to take over the classes, I was surprised by how quickly we all adjusted to the new situation. Alex and Shea, whom she hired to teach as well, have done a great job taking over in a difficult situation, and as far as I can tell, all of us are more than satisfied by their work.

## LESSONS FROM ROLAND PARK PLACE

Fortunately for me, although the upheaval in the Fitness Center was difficult for us all, at the same time a positive change had occurred in my professional life. Mary Alice Wolf, who was in charge of the book reviews published in *Educational Gerontology*, asked me to review a book titled *Women in the Middle* by Elaine Brody, a well-known gerontological scholar. The book was first published in 1990 and then revised and reissued in 2004. I found the interviews with caregivers to be fascinating. Because in my youth my parents did

not live with their aging relatives, I had no idea that so many people felt morally obliged to take their elders into their dwellings, nor did I know how miserable the situation sometimes made the caregivers and the parents as well.

While writing the review, I discovered that in 2010, at the age of 88, Brody had published another article for *The Gerontologist* related to her research in the book ("On Being"). In it she talks about being in a condo for the elderly. Unlike my facility, it had no health care, but it offered her the company of many lively people. She found that most of them shared the same concerns. In her article she mentions how much she was learning from listening to the comments and asides of her new friends. In fact, she reports that "listening and translating what I hear" had become "organized listening (research)" (9). She recalls that years before, when she had talked to interviewers of older people, they advised her to pay attention to the subtext of what the people were saying, their "cries, whispers and silence" (9). When she moved into the condo, she acknowledged that she was "a very very old person" (9). For the first time she could make direct use of her own experience, in combination with the wealth of knowledge from her professional life. She learned that older people did not like it when their adult children tried to take over the decision making about their lives. Since I was in a situation similar to Brody's, being a gerontologist who lived in a CCRC, I was enormously impressed by her work and felt that my efforts were supported by her decision to continue doing research while she was in the condo.

As a result of reading some of Brody's research, I began to understand that the upheavals at RPP could be of interest to other gerontologists. Most important, the loss of Valencio taught me that those who move into a CCRC which has managers, like Roland Park Place, to a certain extent have traded autonomy for the promise of long-term care. In many ways we are dependent on our institution's employees, a situation that was unnerving when Valencio was forced out of RPP. We have learned that we might face unpleasant situations in the future as well. On the other hand, those who run our place do not want unhappy residents who might discourage newcomers from moving in. As a result, they do take action when residents are unduly upset by what is happening.

Therefore it is most important that would-be residents move in early enough to learn which employees are reliable. Some behave like Atul Gawande, the author of *Being Mortal*, who discovered that he could not help patients unless he asked what made surviving worthwhile. Fortunately, a good many employees want to be helpful and sometimes go out of their way to do so. Others are indifferent to our feelings, and a few rarely speak to residents. Despite that, in time those who are in charge of this place eventually discover that some employees behave in inappropriate ways and as a result decide to part company with them.

I think we residents have to learn to be resilient and resourceful when things seem to be going in the wrong direction. Patience is a very important virtue. Recently, a new employee in the dining room ruffled quite a few feathers. A friend wanted to organize an official letter of complaint signed by many people. I thought that we should wait and see what transpired. As it happened, we learned quite recently that the employee is no longer working here. Apparently, enough individual complaints about his behavior had convinced the authorities to accept his resignation.

Moreover, we are facing a difficult time now that the building is being “repositioned” in order to make RPP financially viable. Most of the rooms on the first floor are being moved around, and some second floor rooms are being changed as well. Once that part of the job is completed, a new section of apartments and parking spaces will be added to the old building. Once again, we residents think that some of the problems of the construction might have been handled more expeditiously if residents had been consulted sooner. Fortunately, however, we recently learned that the architects plan to expand the part of the Fitness Center where our large classes meet. For the time being, the problem of inadequate space has been well handled since the company took over. Alex and Shea doubled the number of classes taught each day. As a result, rarely does a resident find too little space in the classes. Most people are very pleased with the new schedule, and the number of people attending classes has increased.

Of course, having a building under construction is not much fun. On the other hand, some of the changes will allow RPP to offer a more advanced kind of memory care by reconfiguring the assisted-living apartments and health-care rooms. Instead of long corridors, there will be some pods, small groups of rooms around a common room that will permit the employees to work more one-on-one with residents who have dementia.

Like Gawande, I think one should try to find out what qualities of life really matter to the individual. It makes sense to encourage aging people to explore the possibilities of a variety of retirement options when they are young enough to adjust to a different place and a new group of people. It matters what choices we make while we still can do so.

I don't know if I had anticipated the kinds of friendships that I would make at the time we moved in. But as time has passed, I realize that what makes RPP work for me most of the time is the comfort of friendship and companionship. I have had many interactions with residents and some employees that are delightful. I discovered that in times of trouble we can count on people to be supportive. Many residents have lost family members or had health issues that frightened them, so they write notes or say kind things when one's spouse dies or we experience serious health problems. Unlike the outside world, which can make older people feel invisible, as Roger Angell reported in a 2014 article in

*The New Yorker*, fellow residents do not dismiss us. They offer condolences and good wishes in times of trouble.

A group of us eat many meals together in the café and enjoy meeting for Sunday brunch in the main dining room. As a result, we have gotten to know each other very well. Sometimes the conversations are extraordinary. Some Sundays ago, Sally, one of the regulars at brunch, started to mention *The Nightingale*, a novel she was reading about Vichy France in World War II. From that beginning she told us about family members who found themselves trapped in the same place when the war broke out. Some managed to escape, but others did not. Although these tragedies happened many years ago, the feelings they evoked in her were fresh. At times she said that she couldn't continue to tell us what had happened; it was too painful. I think we all realized that we were having a most moving and unusual conversation that could not have happened if our friendships had been superficial.

In conclusion, gerontologists need to draw on their practical experience with aging relatives and friends who have discussed what it is like to live in the many different kinds of places that are currently available for older people. Like Golant, who visited the places he wrote about and interviewed residents, we need to combine our knowledge of the field with our personal observations. Without a combination of the academic and the personal, we will not be able to assist others who are facing the same choices that we confronted.

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## **Part 2:**

### **Working and Playing in the Care Home**



Betsy Struthers

## SECOND SITTING

So many of their names begin with “M” and so many are or sound the same – four Margery, three Margaret, two Mary, a Martha, a Marilyn, a Marie. No wonder they forget who they are, where they’ve come from, what they’ve done and been. Words choke up on them, they can’t hear each other speak. *Stop whispering*, they hiss. *Well, excuse me*. One coughs into her napkin, one wipes her weeping eye. Canes hooked on chair backs, walkers parked by the wall.

A daughter joins her mother for lunch, is introduced as the youngest, the oldest, the one in the middle. She sits with her knees pressed tightly under the drape of white vinyl, feet on the floor, elbows off the table. They watch her chew and swallow, note how often she empties her water glass. If she wears beads or pearls. How many rings. Now she is introduced to Margery again. Who asks *who are you?* Says *beware of the fourth floor*. Who pleases *it’s time to be going. Take me home*.



## Shelter in Place

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Laura Dunbar

When I turned 35 years old and could no longer avoid the fact that, unless I did something big in my life, not only were things not going to get better but could and were already getting much worse, I enrolled as an adult learner in community college. I didn't have any idea what I wanted to take and I didn't have a high school diploma, so I hoped maybe, at best, to get accepted for a secretary course or something. After I wrote a placement essay and did some other high-school equivalency tests, though, a woman from the registrar's office phoned me and asked if I'd come in to talk with a student advisor. I went to see the advisor: had I ever thought of becoming a nurse? With the help of a third woman, this one a weary but patient financial aid officer, four months later I was in a basic anatomy class for new nursing students.

After the first semester, the regular registered nurse (RN) and the practical nurse (RPN) streams split. I wanted to go on to become an RN and knew by then that I had what it would take to do it, too, but my husband had one of his reasonable dangerous afternoons during which he figured out several times what the hourly wage for RPNs multiplied by forty hours would work out to every week. His calculations confirmed that my new value to him wouldn't be significantly extended by the RN diploma. So he did in his straightforward way what John Dos Passos, in the preface to *Occasions and Protests*, says all responsible adults do, which is to decide which buds need to be pinched off – only Dos Passos meant buds of one's own making, of course, not of other people's, which is a considerably more permanent kind of cautery. But okay. With even a little bit of school, I'd begun to feel like I could stand up straight in the world. I kept that to myself, though.

At graduation, I won an award. The ceremony was the first time my children had seen me at a public event that had nothing to do with them. Within a week I was hired at the hospital, on H2, a general medical-surgical floor. When I got my first pay cheque, I realized I could shop at the Giant Tiger discount store ("for you for less!") because it was close, not because it was necessary. I brought home five Sarah Lee frozen cakes that night and that's what the kids and I had for our celebration dinner. The evening news talked about working Canadians

and for the first time I was in that category – at the lowest end, to be sure, but I was there. If there'd been two of me, we would have almost made a regular middle-class household.

Acute care was good work and if I didn't feel it was my passion, as the Oprahists keep telling women their jobs ought to be, it certainly paid the bills and made me proud of myself. I was surprised and a bit ashamed, then, to find myself getting bored after only a little while. Hospitals nurture routine as a safety check against the malevolent willfulness of human bodies. If you're used to doing the same things at the same time every shift – vitals, check; catheter output, check; dressing change, check – you should notice the unexpected. As a practical nurse, however, the restricted scope of practice that described my role didn't allow me to do much more than report my observations to my RN partner. In Ontario, practical nurses were still not very far removed from the nurse's aide model, and some of the older RNs didn't think we could do anything but empty bedpans and make beds. So, while I could pick up as many shifts as I wanted in wards hit by C. difficile outbreaks, sweating under infection control gowns and being up to my elbows in unimaginable quantities of bloody diarrhea didn't feel at all like the application of the care planning model set out by the great American nursing theorist Sister Callista Roy, which I'd come across in the college library.

There were other surprises, too. All the hospital television shows I'd ever seen made it seem like doctors and nurses were in conversation all the time, when in my experience the separations were distinct and non-negotiable. Doctors visited our floor like Joves muttering among their hinds, mostly oblivious to us except as extensions of their decisions. I found compensation for this class division in another thing the college teachers hadn't told us: that being a nurse is being part of a female guildcraft circle. It was a female circle not just because it was composed mostly of women but also because it revolved on two axes: first, around the theoretical values most often attributed to good mothers – selflessness, patience, service; and second, around the lived experiences that are the outcome of a social belief in those mythic values – most of the circle's members were overburdened with home responsibilities and under-recognized both there and in their work lives. Most importantly for the lives inside the circle, the profession at that time was still shaped in essential ways by an unofficial mentoring model in which experience and intuition formed the foundation of the guild's knowledge and guided its practices.

Secure, close, not always friendly or even pleasant, it was a community with the tensile strength of wire. To the public, it shows only its Nightingale side – nurses are deeply invested in preserving their public historical image – but on the other side of the desk the masks come off. Few people, after all, are capable of professionalism for twelve hours straight.



Long shifts fasten people together. Out of those hours I gained new friends, people to go to the Wing Qing Tuesday buffet with, baby showers to shop for, holiday plans and Sandals cruise deals to hear about, people to dislike and roll my eyes over, divorce collection envelopes to donate money to. I could give my kids book-order money for school and buy them cheaply made but expensive sneakers; I found my fragile youngest child in my uniform top pretending to write in a chart about her hamster. I was a nurse, and that's always a collective noun. I was in my late thirties, and a new life was suddenly breaking over me in twelve-hour shifts. Many people talk about the institution as a site of depersonalization, but for me nursing became my portal of entry to autonomy.

For me, then, my membership in a (semi-)free association was the gateway to my individuality. But there's always a rule, and the rule was this: in the circle, you hold your end. When someone spends her days off at the casino and her breaks scratching tickets, you hold it. When someone loses it with a yappy teenage daughter and goes from screaming to slapping to a fractured ulna and a story to the ED doctor about a backyard trampoline, you hold it. When the med record shows for the third time on a week's shift run two Ativan refusals ("wastage, patient refused" in neat tiny handwriting) you hold it. You hold it and you hold on; you don't go to those panoptical egrets in Human Resources. Because the circle's only as good as you are, and before long you'll see that it's working for you, too. When my husband, indefatigably circular in his logic as only the very stoned can be, called the desk every hour on pay day, it locked in place around me, immoveable, impassive, impenetrable.

The circle was red-tent succor and it raised in me a belief in the power of groups of women who understood themselves to be basically alike because they worked together and took from that work to the rest of their lives sources of individual identity and group strength. Years later I would learn a word, "reification," that would make me question the ways and means of those identifications and the tenuous foundations upon which that strength rested. But while the circle was around me I felt only its security.

I didn't know then that the circle was already dissolving under the pressure of a health-care system driven into the ground by financial problems and by attempts at solutions that would get rid of the informal guild tradition forever. In its place was emerging a version of nursing professionalization that was the function of a strangling desire for measurable outcomes and which, though it advocates patient-centredness, actually alienated nurses from the people who depended most on them.

That discovery was some time away for me. At that moment, I was on the bottom of the seniority list, and I was frustrated by my restricted scope of practice. Luckily, the demographics of our town were in my favour. Most of H2's patients were elderly; many of them wound up there, whether they knew it or not, as the first stop on a path that would see them placed in long-term care.

I watched how this worked for a few months; I had liked my student clinical rotation in the local nursing homes. I sent off another set of applications, and in under a week I was hired again.

My new job was at a just-opened long-term care facility located in the heart of a rural village north of our city. The region's lakes and woods made it popular with summer cottagers, but many of the locals were struggling after downsizing at several factories had left their major wage-earners with fewer hours or out of work altogether. Given the setting and the times, the addition of a state-of-the-art care facility had made local headlines, and the building's construction had attracted many sightseers. In fact, in both theory and practice, the home was innovative, reflecting some of the newest theories in contemporary geriatric care.

Next to the reception area, a shared outdoor courtyard formed the hub of the building. From it radiated, in geometric petals, four home units of 25 rooms each. All four of these wings eventually looped back to the hub; the idea was that wandering residents could walk freely around the whole building without getting lost. Each unit was named after local parks or waterways and had its own nursing station as well as its own dining room, medication cart, and supply room. In the hub, there was also a hair salon, a private party room, an open-access kitchenette outfitted with a toaster, kettle, and a fridge so that residents could fix their own snacks or hot drinks, an activities room with a television and a kitchen equipped for more serious cooking activities, and an enclosed smoking room with heavy flame-proof aprons hanging from hooks. Sliding patio doors lined all sides of the central courtyard and the smaller gardens in the centre of some of the individual units' wings; although they didn't open more than a crack for safety reasons, in the summer the doors let in fresh breezes and they made the halls and dining rooms bright even in the winter. Courtesy of the local animal shelter, for a few months there was even an amiable obese cat.

Because it was provincially funded, the facility fell under the purview of the Ministry of Long-Term Care, so one of its essential obligations was to meet the Ministry's standards. Central to this mandate, the Resident Bill of Rights hung in the reception hall near the Director of Care's office and set out what residents and their families could expect, in terms of both the standard of care and the delivery of that care. Also because of its provincial designation, the facility was committed to accepting residents whose care needs were substantial.

I liked it from the start. Once my probationary period was over, I became the regular relief for a full-time RPN, so there was a sense of stability and security to my schedule. I enjoyed working with the same team of Personal Support Workers (PSWs) and getting to know the residents and their families. Each RPN was assigned two wings, or fifty rooms, and worked with two pairs of PSWs, one pair per wing. The med cart was my primary job responsibility, but when I

was done giving medications to fifty people two or three times in eight hours, I could do wound-care assessments and treatments, update care plans, process orders or review the narrative notes in charts and leave requests for the doctor. Our house doctor was a grave, conscientious man who talked to the staff seriously about what we thought should be done. The complex needs of our patients demanded my attention not just to their physical conditions but also to their psychological, social, and spiritual needs. I found the mental exercise and the intellectual discipline enormously satisfying. I became more secretive at home.

The burden of physical labor – and it was a heavy one – fell on the PSWs, most of whom were middle-aged women from the village and the nearby countryside. I made a point of helping when I could, and I was proud of the good relationships I thought I had with them, but there is no escaping the fact that the work they did was exhausting labor much harder than mine. The tasks they were expected to perform in pairs in a single shift would have challenged twice as many workers half their age. For example, two day-shift PSWs were expected to have 25 people washed, dressed, and in the dining room by 8:00 every morning, when their shifts began at only 7:00 and when at least twelve of those people could, to varying degrees, be what we called in the care plans “resistant to care,” a euphemism that could mean anything from dead-weight stiffening to pinching, spitting, slapping, or kicking. If a resident didn’t attend a meal, it was my duty to find out about it and write the reasons the PSWs gave in the chart and tape them for the RN report. Another major discouragement to leaving recalcitrant residents in their rooms for a meal was the requirement that at least one PSW then feed the person in the room, which left her partner alone in a dining room to serve and help clear every course as well as to feed perhaps five or six people at risk from various problems related to dysphagia.

Not surprisingly, I saw that the PSWs often felt about us, the RPNs, the same way we felt about the RNs in the hospital. I tried to let them know I appreciated the work they did, but I knew they were skeptical. I didn’t blame them for suspecting insincerity. We worked together and relied on each other too much for me not to know how unfair it was and how often they got hurt on a shift. Unlike the hospital, all the staff in the home got to know each other, and well. In the hospital, we almost never talked to the housekeepers or lab technicians who worked on the floors with us, let alone the kitchen staff who would every day bring and remove the meal trays. But in the home, you took your breaks with everyone else. Not infrequently, many of the staff who worked there were friends or even relatives outside of work, too. So the circle in the home took on a different quality, one that was more intimate in some ways but also more diffuse and unpredictable because it included people from different work categories. There were also those definite and widespread ties to the local community outside the home, which didn’t apply at the hospital. My husband had grown up in the village and was well known to many of the staff members’

husbands and therefore to the staff members as well. As Alice Munro knew, when I was offered rural Ontario kindness I was also obligated, on occasion, to welcome reminders of my shame.

On days when I wanted to avoid the staff breakroom, I would eat my lunch in the medication supply room and then wander the halls looking at the display boxes mounted outside each of the residents' rooms. It was a way for me to get to know who these people were and what they had been like in their "before" lives. When I was behind the med cart, I had so little time to do anything but make sure I was getting the right med into the right person that it made me ashamed of my rudeness. The residents who'd been there for some time knew that I didn't have time to talk beyond the briefest courtesies, and so they wouldn't bother many times to do anything but open their mouths automatically. For this and other reasons they reminded me, fancifully, of birds, bright-eyed but mostly silent during my med passes. In my imagination, I began to see them as different species: Jean was a crow, watchful and ingenious; Beth was a chickadee, cheerful and busy; Jim was a jay, ready to pinch or squawk. Suzanne and her cousin Mrs. Norbert were sensible agreeable hens, always together, fussing over each other's families and busy about the hallways, their walker baskets filled with snacks and Kleenex and festooned with the grandkids' beaded lanyards. Callie was an ostrich: large, fast, and dangerously able to grab ponytails and yank hair out or kick hard on her way by. Ted was a disparaging aloof swan.

As the months passed, of course, I got to know people outside of the medication cart routine, and with some I formed connections that were a great deal deeper. It is not an exaggeration to say that I loved many of them then as much as I love my children or my current husband. I carry them with me, even though it's been years since I let my registration lapse.

Jenny's husband died at 45, leaving her with a 50-acre dairy operation and three boys. Work and prudence had been her life's watchwords. As the scourge of her dementia burned away at her, she would name us by what she knew: I was Pill or Walk; the PSWs could be Bath or Sleep, Snack or Kiss. Sometimes we were Bad or Cow. As can be the case, her dementia touched many things but left other elements of her personality intact. Before the dayshift arrived, she'd already be washing down the counter in the kitchenette with a dry rag. By the time I went looking for her after morning report, she'd have finished that job and moved on to wheeling herself into other residents' rooms, exhorting them in her way to get up and get ready for school: "Bus!" When she saw me, though, she'd leave that to wheel herself along behind me as I pushed my med cart – did it remind her of a tractor or a wheelbarrow? She'd wait patiently outside each room while I checked and poured or counted and recorded. When I turned the cart's lock and made to push again, she'd nod calmly at me as if to say: "Yes, that one's done right, now on to the next." At the end of the pass, I held the med-re-

cord book for her to look at, and would be rewarded by another nod: "Yes, all good here; let's go."

Like me, on a bad day she could be comforted by kittens – though the actual cat had been rehomed after an unfortunate hilarious incident involving its litter box, we kept a supply of fakes and Jenny and I enjoyed them together. Jenny loved pictures of kittens, her stuffed kitty, and talk about kittens. It made me happy to think of this tough woman running her farm by herself, raising three strapping rowdy boys, taking no nonsense from anyone, and stopping to pick up and cuddle each of the barn kittens as her dignified middle son, now in charge of the farm, told me she'd done every working morning of her "before" life.

Sometimes, when I was done looking at my lunchtime display boxes and still had interminable break minutes left, I would find Jenny. She'd pat my arm, gentle as a mother, and for a second I thought I could feel both our minds uncloud. Her sharp eyes looked right into mine. I knew she was suddenly fully present and not just present but present *with me*. For a split second, she knew all about it, all about me, and she was sympathetic. Maybe it was projection on my part. I can imagine an argument that would charge that I'd let my own need impose itself on another helpless human being, and that doing so diminished her right to be herself. I don't know. To me it felt like Jenny and I were there together, even just for a second.

Norma, on the other hand, had once owned a movie theatre with her husband and had been a ballroom dance teacher. Whereas Jenny's display case was stuffed full of family bric-a-brac, and her daughters-in-law regularly edited and re-stuffed it for her, Norma's display box held nothing but a single old photo of her in a tweed pencil skirt, two fat dachshunds in her lap, hair pulled back, modish black-framed glasses framed by dramatically plucked brows. Even in black and white, you could see she'd been wearing plum lipstick. Norma had had a stroke and was silent and contractured, her hands curled into sparrow's claws. Her supply of clothes was basic and ugly: she had no daughters-in-law to fuss and choose. Every time I looked at her, I saw the vivid plum-coloured woman in the photograph, laughing back at the photographer. I still don't know why, but I found her, like Jenny, inexplicably restful to be around. When I had desk work to do, it became my habit to bring Norma with me and park her chair beside mine. Once every month or so, her husband would come and find her sitting with me and he'd take her back to her room to visit. Norma was slight and could still bear her weight with help, so it was easy for him to put her back to bed by himself when he was done visiting. When we saw him leave we'd go in and wash her. Pull her pants back up.

Sometimes I thought she was looking at me, and other times the PSWs would say she'd whispered something to them, but we could never tell for sure. As her conditioned worsened and it became clear that she was actively dying, I wanted to be with her as much as I could. On evening shifts when the last med

pass was finished, I would go to her room and check on her; if I felt she was awake I'd talk to her. I needed someone to talk to. I'd registered for classes at the university and was being upset every week by new ideas. It seemed like Norma would understand how life can crouch at you one minute and in the next unveil possibilities you'd never imagined. I felt both more helpless and more powerful with every passing month, caught in the synapse between an unspooling past and a violently gathering future. The storms were rolling across my mind. The plum woman in the photograph raised her eyebrows at me and laughed.

I was taking a poetry survey course and had begun to whisper some of the verses to myself while I was caught up in the rhythm of my med-cart work. I liked knowing the lines, turning them over and over till they were smooth – for every poem I memorized I promised myself I could get rid of for good one of the stones I habitually carried in my pockets. One stone at a time, I was growing lighter.

One evening near the end, I was with Norma and trying to remember the last line of a poem the professor had read to us that week. I struggled out loud, went back to the beginning: “A loaf of bread, a jug of wine / A loaf of bread, a jug of wine” – loaves and jugs. Nothing. It was time to go and tape the last report for the night shift. A new charge nurse, who had worked on quality assurance with the Ministry and who had never heard of circles she didn't want to smash, had a rule in which unscheduled time with residents in their rooms could get staff written up. I said goodnight to Norma and turned out her light.

In the darkness I heard it. I heard her.

*And thou, singing beside me in the wilderness.*

For a long time after I quit, I'd have this dream. I was hurrying through the home's halls looking for something, I don't know what, while a clever alert thing loped up on me, got closer behind me, was slipping along the wall only one corner away now. In the next instant I'd find myself back at the hub. The door to the garden was wide open: a million bright birds were floating, hanging in the trembling singing air. It was open for me, too. I could go in to that circle. All was well. I went through. Between Jenny and Norma, I'd sit and we'd listen.

Norma, I hear you.

Author's note: Some readers may wonder about the ending of this work of creative non-fiction. While it is true that I left this job shortly after the events described at the end, I left only because I was offered a position with more hours in another long-term care facility. Like many nurses, my dependence on the profession outweighed my unhappiness about specific circumstances. Even though more than ten years has passed since I gave up my registration, those tensions remain, though mitigated somewhat by the passage of time and by the significance I now know nursing had in my life.

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# Long-Term Care for the Future

## Just What Is Real Anyway?

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*Peter J. Whitehouse*

Aging represents both a demographic challenge and an opportunity to reinvent the story of humanity in a new way. As a geriatric neurologist involved in the clinical care of persons with dementia and in prevention and public health, a cognitive neuroscientist studying both dementia and wisdom, and an ecologically oriented bioethicist concerned about a sustainable future for our species and others, I see aging and care as important issues in themselves. However, they also have a role to play in leveraging culture change, not only in long-term care but also in society at large. Much-needed genuine hope for the future can come in many forms, but we must be vigilant about detecting unreal false hope (like biomedical models of curing age-related conditions such as dementia), instead building up real true hope, for example by adjusting our expectations about inevitable material and scientific progress based on unlimited resources.

We need to think long term and with care about caring, across the life course, through time, and around the globe. Hence, the focus of this *Care Home Stories* book has significant implications for the broader challenges that humanity faces in today's world. Examining the challenges, changes, and continuities of care home stories in the narrowest context of people's experiences in places identified as providing enduring care, like nursing homes and assisted living, is an important enterprise in its own right. However, as in every field of human endeavor, it is critical to examine the widest context for the evolving changes in any narrow domain of human activity by examining the patterns in culture and nature in which those changes are embedded. With the current intense global connectedness of the world of ideas and the world of nations and communities, it is all the more critical to look at problems and potential solutions from a big picture perspective, that is to say as systems thinkers and not as narrow specialists. This broader shift characterizes the evolution of my own thinking from being a neuroscientist studying brain nuclei and pharmaceutical interventions to being a change agent in relation to the flourishing of human and other life.

Our future survival depends on our ability to see intergenerative connections between modes of thought and action, between professions and disciplines, and between communities of diverse composition. *Intergenerative* is a word we coined (see below) to signify going between sources of cultural generativity (like intergenerational and interdisciplinary or even transdisciplinary) to create innovations in thinking and valuing. We are in a world where we must reflect deeply on our experiences and imagine more connected and healthier societies. Trusting and sustainable relationships are key to the intellectual and value explorations and reflections. This reimagining of aging and care is the subject of this chapter that describes relationships with two personal mentors and three related experiences in long-term care.

## **MY LONG-TERM MENTORS: SID KATZ AND JOE FOLEY**

My long-term care home experiences began with two mentors, Drs. Sid Katz and Joe Foley. The lessons I learned from these two wise elders colored not only my professional career engaging with nursing homes and assisted living but also my sense of who I am as a human being, especially now as an emerging elder. Relationships, particularly those between people of different generations and different life experiences, are key to human flourishing as individuals and as communities – a theme to which I will return later.

Sid Katz was a distinguished geriatrician – a member of the National Academy of Medicine. He developed the Katz ADL scale, which is still a widely used instrument to assess the functional capabilities of older people in the community and in long-term care. He was the first author of the Institute of Medicine (now the National Academy of Medicine) report that transformed the way we think about assessing and changing nursing homes. The report, entitled “Improving the Quality of Care in Nursing Homes,” led to fundamental changes in the structure, process, and outcomes of care and reimbursement of nursing homes. It also motivated the development of the Uniform Minimum Data Set (UMDS), which nursing homes were required to collect in order to measure quality of care. I actually worked on the Cognitive RAP (Resident Assessment Protocol) that is part of the UMDS. Dementia is a common condition in long-term care, and my practice caring for people with cognitive impairment motivated in part my interest in long-term care and working with Sid.

Sid chose his words carefully, because clarity of communication was critical to how he shared his theoretical ideas. He was Jewish, a fact that emphasized his rabbinical nature: he was a true teacher, one who sought out young people to mentor. We wrote a paper together (Whitehouse et al.) on the relationship between wisdom and quality of life, a concept that continued to be a dominant

theme in my own scholarship and engagement in life. One key lesson I learned from Sid was when he told me how he imagined the changes that might occur in nursing homes based on his work, but that they would not occur until long after his own death. This sense of long-term thinking past one's own personal mortality stuck with me. It also influenced my thinking that you are not socially dead even after you have ceased to breathe, in the sense that your story goes on beyond personal mortality. The idea of legacy became key as I thought about my own career and the lives of my older patients. Legacy was a name and a concept that I used in many of my later long-term care intergenerational projects, as described below.

Joe Foley was almost the polar opposite: a neurologist with an Irish sense of humor and concern for the particular. He was actively Catholic but culturally irreverent. He was a storyteller and would share his past adventures in Boston Catholic schools and in his neurology residency with some of the early neurological greats at Harvard. He was a model for committed patient care and for not putting up with nonsense. He once told me that I should say little about nursing homes until I had actually lived in one. He thought that the UMDS caused too much paperwork and took nursing assistants and nurses away from patient care. Joe's stories were all about the past – his past mentors and students. So if Sid oriented me to the future, Joe taught me the value of understanding your roots. To exaggerate a bit, Sid was a man of future ideas, Joe of past stories.

Both of them transformed my thinking. My early career had been successful as a neuroscientist describing brain changes in patients with Alzheimer's. I was a leader in developing drugs to treat people with dementia. However, both Sid and Joe allowed me to see the bigger picture. As the power of pharmaceutical and genetics models and economics corrupted the biomedical field, I became concerned that false hope based on promises of pharmaceutical fixes were seducing us. One phrase I came to dislike was "care today; cure tomorrow": it implied that we just needed to invest enough biological research dollars to eradicate the problem of Alzheimer's, and hence care would become outdated. By that time, it was clear that our understanding of dementia was confused and that Alzheimer's was composed of a diverse set of processes intimately related to aging that drugs would not effectively address. Hence, care today *and* care tomorrow are critically important. Besides, I came to realize that if we improved the care of people with dementia, we would improve the quality of life for all of us. Caring for persons with dementia opens opportunities for individual and community growth.

## **FIRST LESSON: THE FLOOD**

My first story in long-term care begins when I finally took Joe's long-offered advice and lived in assisted living in Toronto between 2011 and 2013. As part of my fieldwork as a strategic advisor in innovation to the CEO of one of the University of Toronto's hospitals, I was a part-time resident in The Terraces, an independent/assisted-living facility that is part of Baycrest Health Sciences. The Terraces was a lesson in the reality of the future of long-term care in many ways, but one stands out for me. During my stay, a powerful storm flooded the transformer in the basement, forcing the evacuation of the residents to various locations depending on their level of frailty. I was prepared because I had just returned from a camping vacation, so I had my headlamp to walk the darkened halls and appropriate clothing and food to weather the storm. The inability to repair the transformer and restore power quickly necessitated an evacuation in which I provided some assistance. Some whose families could accommodate them went home, some who were too sick went to the hospital, and the majority went to the nearby Holiday Inn, a place that I was quite familiar with based on previous visits.

In our Baycrest case, the event ended up being a community-building success as a result of great staff and organizational response, but that is not likely always to be the outcome. These kinds of severe weather events will increase in the future because of climate change. How can we learn from disasters in order to be better prepared the next time? In both Hurricane Katrina and superstorm Sandy, many of the most vulnerable were elders. Decisions about whether to evacuate nursing homes or to allow residents to ride out the storm in place were difficult. Mass evacuations are stressful and expensive. Understandably, circumstances became overwhelming, and in some instances elders clearly died in long-term care (with perhaps some being helped to die through physician-assisted euthanasia).

## **SECOND LESSON: THE UNREALITY SHOWS**

During my career, I visited many long-term care units around the world, especially in Japan and Europe. I was involved in studying SCUs (Special Care Units) for people with dementia. Many tried to help people with dementia feel at home by allowing them to bring personal furniture and mementos when they moved in. One locale took this attitude to such an extreme that I felt a bit uncomfortable – an unreal reality. That place, Hogeweyk, a nursing home in the Netherlands, achieved international media attention by being called Dementiaville. It started a movement called Dementia Villages.

Rather ironically, I visited Hogeweyk with Vicki de Klerk, a leader of the international Validation Therapy movement. Validation asks us to try to see the world through the eyes – that is, the past life and current experiences, of the elder with dementia. The facility creates an environment that is designed to mask the dementia by pretending that the residents are in an earlier time and place, complete with a non-functional bus stop perhaps to fool the residents into thinking they are free to leave. Units were designed to match various forms of Dutch social life (one even mimicked Indonesia for those who immigrated to the Netherlands from the former colony). The community is invited in to shop, go to the theater, and eat at their restaurant.

The project has been compared to the 1998 movie *The Truman Show*, a satirical comedy featuring Jim Carrey playing an adult who had been raised since birth by a corporation and who lived in a simulated television game-show village. This was an early form of reality television. During our visit to Hogeweyk, both Vicki and I were slightly put off, not so much by the several hundred Euro fee for a short interview, but by our guide's apparent lack of interest in our work or our views. Staff seemed to be in a world of their own making and focused on their business model.

The Glenner Centers in San Diego is developing a superficially similar but essentially different project called Town Square. Their planned reconstruction of a San Diego urban environment within a large warehouse involves a place to visit, not live. The sets include a grocery store, a drugstore, clothing shops, an auto shop, museums, schools, and other places one might find in a town square. The project involves creating activities for persons with dementia as well as their caregivers and other family members (and perhaps others). Unlike Hogeweyk, this program seems more playful, where being back in time is a form of storytelling and play rather than fostering an actual false belief of being in an earlier historical period. The opportunity to be intergenerational exists. Play amongst children and elders is something that comes naturally and should be encouraged. Such an environment can foster relationship building and mutual learning.

Town Square links to broader efforts to make communities more dementia-friendly around the world. Most of these efforts focus on helping people with dementia navigate their own “real” community and assist community members to better understand the effects of cognitive loss on their fellow citizens. This process of adapting communities seems more real to me than pretending an entire residential ward exists in the 1950s. The learning that can come from visits to such a living museum can foster flexible thinking; playful reminiscence seems better than serious fakery.

### THIRD LESSON: INTERGENERATIVITY

Whatever you think of reality, today it seems at times to be quite unreal. The United States and other political environments seem full of Orwellian 1984 language games to the point that we now have alternative facts and fake news. The world is changing rapidly and is full of wicked problems, amazing opportunities, and complex challenges that seem difficult to fathom and act upon. Climate change and income inequity would rise to the top for me as problems. We seem to be missing the courage and wisdom to address our current ecological, economic, and social realities. We are becoming more of a danger to our own species and others as we enter the Anthropocene – a geologic age dominated by human activity. Yet maybe we can find the wisdom to foster values and take actions to address these challenges. Never has a hopeful vision for the future been more important to the human species. Reimagining both “aging” and “care” can be a part of this process, with enormous short- and long-term implications for our species. My experiences in long-term care have contributed to my shift in focus from medical to social interventions.

My last and latest experience with a long-term care institution offers a positive vision of the future. It is intergenerational in nature, creating opportunities for children, youth, adults, and elders to interact. It involved two innovative partners, a long-term care facility and a public community school. Judson Smart Living is a long-term care complex closest to the original intergenerational school founded by my wife, others, and me in 2000. My wife, a developmental psychologist, wanted to start a school to serve the needs of disadvantaged children who were not getting a good education in the Cleveland Metropolitan School District. As a geriatric neurologist I felt we needed to create spaces in society for elders in general, and especially those with dementia, to continue to contribute to community.

We both believed that learning was most powerful with a focus on holistic experiences and social construction. We believed that relationships and reading were critical to empowering students to get a good start in life, particularly those born in disadvantaged social and economic situations. We now have three intergenerational schools that have been nationally and internationally recognized for their contributions to the education of children and the brain health of elders. For example, in 2012 we were awarded the Eisner Prize for lifetime achievement in intergenerational advocacy. The pedagogy of our schools involves creating opportunities for children of elementary-school age and adults and elders to form mostly one-on-one relationships and share stories. Reading mentoring involves pairs of different ages that read books to each other or share stories from their lives.

The “Legacy of the Clark Freeway Fighters” was one such co-constructed narrative project. The children in our school interviewed elders who in the

1960s had saved the local nature center in Shaker Heights, which our children often visit, from a corrupt politician who wished to place a highway through it. We published a book of stories and photographs capturing the spirit of their activism in hopes of perpetuating such spirited citizenship in the minds and hearts of our children (Harris and Whitehouse). We published the story as an article in the *Journal of the American Geriatrics Society* entitled “Occupy Nature: Passing Activism across Generations” (George et al.). We also won an award from the Environmental Protection Agency for capturing the pedagogical experiences that we shared with elders in the nature center.

Some of the elders who came to the nature center with us were from the community, but most were from Judson Smart Living. The school bus and the senior transport bus would arrive at the same time, and the naturalist teachers prepared lessons about the importance of understanding our watersheds and other environmental features and community. Essentially the seniors served as mentors for the children, as in our signature reading mentoring program, for example. However, as I learned from Joe and Sid, mentoring can be reciprocal, as youngsters taught elders about computers, for example.

Upon the fifteenth anniversary of our first intergenerational school, we created “The Intergenerativity Project.” With Richard Geer and Qinghong Wei from Community Performance International, we collected stories from many people in the school, including students, staff, teachers, parents, volunteers, and board members. The stories captured the spirit of the school and formed the foundation of a community play called *Moments and Memories* that was performed both at Judson Smart Living and in the school. The title of the project comes from a word we invented to capture the importance of relationships in innovation. Generativity is a word associated with opportunities created by aging and other human activities to bring forth experiences, stories, and potential wisdom gained by an individual. Intergenerativity means bringing sources of creativity together to create something new. We say it is innovation through integration, or “going between to go beyond” (Katz and Whitehouse).

This collaboration between an innovative school and a long-term care partner led to knowledge and wisdom as well as love and compassion. The important message of the story is that long-term care facilities are a part of community, just as schools are. Children and elders are the most vulnerable in our society, yet they represent our past and our future. So too can the power of intergenerational learning and stories enrich our understanding of the possible. Those who control the present – adults – would do well to listen to the full range of human experience and imagination in our efforts to avoid the failure of repeating unsuccessful attempts at addressing contemporary challenges. If we are to create resilient communities that can survive and thrive in response to the social, economic, and ecological challenges we face, it is important that caring for the long term emerge as a fundamental attribute not only of health

institutions and educational programs but also of the entire community. Just as I remember Sid and Joe as mentors, I remember that collective wisdom begins in individual relationships and shared stories.

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# Dementia (Re)performed

## Interrogating Tensions between Relational Engagement and Regulatory Policies in Care Homes through Theatre

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*Julia Gray, Pia Kontos, Sherry Dupuis, Gail Mitchell,  
and Christine Jonas-Simpson*

As an interdisciplinary group of health and artist researchers, we are concerned about the ways in which many persons living with dementia in long-term care homes are invalidated and treated as dysfunctional, thereby promoting social exclusion, depriving them of their dignity, and threatening their quality of life. We are concerned about the ways in which persons with dementia are framed as lost, robbed of mind, doomed, gutted, and the living dead. As part of this, we are conscious of the ways the “tragedy discourse” (Mitchell et al., “Dementia”) is culturally produced through media and artistic representations and the ways it is manifested in care practices and policies in institutional settings, conceptualized as a kind of “social action.”<sup>1</sup> This tragedy discourse is found in mass media, academic, and policy documents and in the reductive and dehumanizing nature of dementia care that is characterized by the management of “challenging behaviours” with mechanical and/or pharmacological restraint (Maust et al.; Dupuis et al., “Pathologizing”).

Theatre and cultural theorist Anne Davis Basting discusses North American society’s understanding and representation of dementia through two dominant narratives. First, earnest scientists attempt to combat an adversarial dementia, if they could only be given enough time and money to fight for and find a cure. As an example, Basting draws on the 2004 documentary film *The Forgetting*. Here Alzheimer’s Disease, as the most common form of dementia, is a “slow and silent killer” that “draws the curtain over the patient’s life and pulls family

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**1** | As critical researchers, we understand that this term generally has more positive, disruptive associations. For the purposes of this chapter, we conceptualize “social action” broadly, as “a thing done or created” following particular, normative social assumptions, in this case care practices and policies in institutional settings.

into its devastating grasp.” The narrative of the film follows the scientific race to discover the cause of the disease and how to cure it, citing broken families drowning in its wake as the reason for the quest (Basting 35–36).

The second dominant storyline that Basting discusses is the loss of an exceptional, accomplished (and probably inspiring) person who is slowly emptied out by the destructive disease. She cites the example of the media’s coverage of President Ronald Reagan’s diagnosis of Alzheimer’s Disease, which conveyed a tragic fall of Shakespearean magnitude. And while perhaps this coverage brought awareness to Alzheimer’s beyond any public service announcement, magazine article or book, it also impressed the high stakes “then/now” tragic storyline deep into the North American cultural landscape.

These conceptions of dementia as produced and perpetuated through media and artistic representations have profound implications for policy development in long-term care homes. In Canada, long-term care homes are governed by provincial legislation, which attempts to standardize care and accountability and requires homes, their management, and staff members to operationalize codes of conduct through institution-specific policies and practices. In the province of Ontario, long-term care homes are expected to satisfy as many as 400 rules (Ministry of Health and Long-Term Care). For example, it is quite alarming to us that the Long-Term Care Act of Ontario has several hundred pages of standards and expectations relating to numerous aspects of care, except for a standard about meaningful relationships and supporting living. A similar critique has been articulated by Julia Twigg in the context of the United Kingdom; she argues that care time is defined in terms of easily measured tasks, where written standards pertain to the execution of tasks and the allotted time spent on any given task (Twigg, “Deconstructing”; “Carework”). Timeframes for bathing, eating, and restraining are marked out in detail, but not those for loving, relating, and thriving. As Kontos and Naglie state, citing Crawshaw: “The rationale of economic efficiency creates a system wherein the measure of care lies with the physical task rather than the quality of human interaction and, as a consequence, the relationship between the care provider and recipient is not quintessentially one of caring” (550; see also Thompson, “Towards”).

Furthermore, there is a statement in the Ontario Act which implies that restraint and force are acceptable if used to complete bodily, physical care. This physical care is understood to override all other kinds of care at the risk of both the resident’s emotional well-being and the relationship between resident and health-care worker. Additionally, the growing risk-aversion culture of long-term care has led to the production of organizational policies that result in the social exclusion and isolation of older adults living in long-term care homes from broader communities. As an example, research shows that some long-term care homes in Ontario have stopped all outings outside the home setting, citing that

the risks of a resident becoming injured or lost are too high for the homes to take (Wiersma & Dupuis; Dupuis et al., “Creating”).

In order to disrupt the tragedy discourse that underlies both cultural production (such as media and artistic representations) and social actions (such as policy development), we embarked upon the creation of a research-informed play, *Cracked: New Light on Dementia*. *Cracked* was developed to open up a playful, social space to raise questions about current conceptions of dementia, expose unjust care practices and policies, and facilitate the envisioning and inspiring of an alternative care culture in which compassionate relationships and supporting living are at the core. We aimed to use an art form – theatre – to engage both each other and audiences intellectually *and* emotionally, by exploring stories, emotional and sensory experiences, theoretical concepts, and research findings within space and time (see Thompson, *Performance*; Boal; Rossiter et al.; Mitchell et al., “Research-Based”; Jackson; Mitchell et al., “Experience”; Kontos and Poland).

The theatrical form, when engaged for social and personal change, holds the potential to provide an aesthetic space for audience members not only to engage critically or analyze concepts and ideas intellectually but also to engage aesthetically, including emotionally, sensorily, and imaginatively. Through theatre, audience members can be provided the opportunity to reflect on how their thoughts, feelings, and senses extend to actions, including representation and policy (Gray). Critics discuss how linear, discrete educational and knowledge translation initiatives tend to overlook complex interrelationships among taken-for-granted assumptions, including what is felt and sensed, and social and personal actions (Kontos and Poland; Shor). We were therefore looking for a way for all involved to vulnerably and safely explore dominant tragic assumptions, including how individual actions (such as how one might engage a person with dementia in conversation) and social actions (such as policy) might reproduce those assumptions. We were additionally looking for a way to imagine possibilities for alternative ways of engaging with persons with dementia as filled with potential.

In this chapter, we explore two scenes from *Cracked* in order to better understand our use of the theatrical form to provide such an exploratory and reflective space. The first scene portrays residents dining in a long-term care home engaging with each other with humour, mockery, foolishness, kindness, and even some *unkindness*. The second shows a health-care provider being interviewed in comical, heightened film noir style by two “Interrogators” for using an affectionate term with a resident. We will highlight how the first scene captures the ways persons living with dementia are theatrically performed as filled with capacity to engage meaningfully and relationally, and how this sits in tension with the regulatory landscape of long-term care that suppresses this capacity in the second scene.

## **CRACKED: BACKGROUND**

*Cracked: New Light on Dementia* was initiated by authors Sherry Dupuis, Gail Mitchell, Pia Kontos, and Christine Jonas-Simpson, all of whom are health researchers who specialize in the areas of aging, dementia, and research-informed performance (as live theatre and/or film).<sup>2</sup> These researchers were looking for a way to challenge the discourse of tragedy and loss that is dominant in relation to dementia and the people who live with it, as well as the corresponding dehumanizing care practices that are prevalent in so many institutional care settings. With playwright and theatre director Julia Gray as artistic leader, the play was developed collaboratively with a group of actors.<sup>3</sup> It emphasizes the centrality of relationships and humanity when providing care for persons with dementia and the need to recognize the dynamic and fundamental ways in which memory and self-expression are embodied. This collaborative play making, or “theatrical devising,” involves an improvised creative process among those working in studio (Barton and Wells; Filewod; Mitchell). At strategic points throughout our process, we continued to invite community members, including persons living with dementia and their family members, into rehearsal for open discussion and feedback about what we were creating. For example, early on in our process we conducted a full-day arts-based workshop where the actors, playwright/director, researchers, and visual artists came together with people living with dementia and family members to interrogate the tragedy discourse and imagine and construct alternative representations based on the lived experiences of people living with dementia (S. Dupuis et al., “Re-claiming”). For more information on our development process, please see our published script (Collective Disruption).

*Cracked* follows two storylines, those of Elaine Carter and Vera Nolan, both of whom have been diagnosed with dementia. The play opens with Elaine’s diagnosis and follows her journey with her two adult children as they navigate their changing relationships. We see Elaine becoming engaged with her community, reconnecting with her longtime friend Vera who has also been diagnosed with dementia, becoming a political advocate to improve the lives of persons with dementia, and flirting with beautiful young men. A space opens in a long-term care home, so Elaine and her family make the decision to move her

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**2** | For examples of our team’s work, please see Mitchell et al., “Research-Based”; Mitchell et al., “Experience”; Dupuis et al., “Re-claiming” and “Catapulting”; Kontos et al., “Improving”; Jonas-Simpson et al.; Mitchell et al., “Dementia”; Kontos et al., “Presence”.

**3** | Actors involved in the initial creative process included Susan Applewhaite, Lori Nancy Kalamanski, Tim Machin, Mary Ellen MacLean, Mary Claire Frances Muir, Mark Prince, and David Talbot. The team would also like to recognize Jerrold Karch for his creative contributions.

into this home. From here the journey shifts as Elaine's world again opens up to meeting new people and making new friends in the home. Elaine's daughter Caroline struggles with her own assumptions of what persons living with dementia should be like; by the play's end she is able to spontaneously dance with her mother. With Vera, the second protagonist, we also witness her journey with her husband, Tom, as they work through changes in their relationship. There comes a point when Tom is no longer able to care for Vera, and she also moves into a long-term care home. As the play moves to the end, and as Vera progresses further on her dementia journey, we learn about Vera's history and life experiences through her sensuous and embodied memories of dancing, singing, joy, and fear. Through both storylines, the audience sees both characters who are living with dementia grow and learn, not only despite the disease but also because of it.

## THE SCENES

For the purposes of this chapter, below we have included detailed descriptions of what the actors are doing in the scene, including their posture, facial expressions, quality of movements, and so on, in addition to stage directions and the spoken text.

In this way, the following is not a traditional script, which would strictly adhere to basic stage directions (basic descriptions of where actors move and what they are doing on stage, such as moving a prop). We include more here to indicate what is missing in written form, the body and its gestures, as integral to performance. Our descriptions of actors' bodies and gestures are also integral to our arguments about dementia: that we overlook the body and its gestures because we undervalue them, and we thus overlook how persons with dementia use their bodies to continue to express and be themselves despite cognitive memory loss.



Fig. 1: Scene from *Cracked*, photographer: Dalia Katz. Actors from left to right: Andy Pogson, Mary Claire Frances Muir, Susan Applewhaite, David Talbot (standing), Lori Nancy Kalamanski, Mary Ellen MacLean, Tim Machin



Fig. 2: Scene from *Cracked*, photographer: Dalia Katz. Actors from left to right: Andy Pogson, David Talbot (sitting), Tim Machin

## SCENE 17 – Dining

*Dining room.*

*During the scene transition, the six chairs are set up as if they are around two square tables (which are mimed/imagined) along the downstage area. All props, such as mugs of tea and meals on plates, are mimed.*

SILAS, a resident, enters from the upstage right corner. Donning a sweater vest which hangs open off his shoulders, SILAS walks downstage and clutches each chair as it is placed around imaginary tables by the other actors. His face filled with intensity and concentration, he carefully limps as he walks from chair to chair, making his way to the downstage left table.

ELAINE, vibrant and active, enters from the upstage left corner. As she sees SILAS limp towards his regular seat at the table, she extends her arm and speeds up towards him so she can help him sit.

ELAINE      Here you go, Silas.

*ELAINE pulls back her own chair at the same table and sits with ease.*

JIM, staff of the long-term care home, is helping ESMERELDA, a resident, to the stage right table. ESMERELDA's arm is hooked into JIM'S and they are happily chatting to each other as he leads her to the table. ESMERELDA's short steps are compounded by the hunch in her back, which prompts her head to slump forward slightly.

JIM            (as he helps her sit) You're OK?

ESME        Yes.

*JIM bustles off to stage right to check on something in the kitchen.*

HENRY, a resident, enters miming using a walker from upstage. As he makes his way to the stage right table, his steps are small and tight as he relies on the mimed walker to support him. Sitting with great weight, he nimbly folds his walker and places it behind his seat. He turns to the others at the table with a big smile.

SARAH, a resident, has entered from upstage right, and walks towards HENRY and ESME at the stage right table. She saunters into the dining room, gently fiddling with the edges of her scarf and softly humming to herself. DOROTHY, adjusting her hair and pearl necklace at her sternum, has meekly entered from upstage left and joins SILAS and ELAINE at the stage left table.

*Residents acknowledge each other as they sit, some chatter to each other, some just sit and smile, some fidget. SARAH continues to hum to herself.*

ELAINE      *(with a laugh)* I'm so hungry I could eat the leg off the Lamb of God!

*Mortified, DOROTHY crosses herself and begins to pray, and SILAS scoffs at ELAINE's absurdity. JIM enters and stands at the top of the table.*

JIM              So, who's for tea?

ELAINE        Oh, me!

SARAH        *(shakes head)*

DOROTHY *(raises hand)*

ESME          Yes.

JIM              Silas?

SILAS          Coffee.

JIM              Henry?

*HENRY, who flirts head to head with ESME, does not respond.*

JIM              Henry?

HENRY        *(looks up in surprise with a big smile)* Oh. No thanks.

JIM              *(nodding, anticipating each resident's preferences)* OK, three teas and one coffee *(starts to exit)*.

ELAINE        And a little sugar into it!

*JIM waves at her as he exits.*

ELAINE        *(turns to her 'audience' of the other residents with a big smile)* So, that guy was so tight, he was tight as a frog. And you know how tight that is?

ESME          No.

ELAINE        Water tight! *(slaps the imaginary table, laughing)*

ESME          *(with a groan)* Oh ...

*SARAH, HENRY and DOROTHY laugh at ELAINE's terrible joke.*

SILAS          Sshh!

JIM              *(enters with trolley with tea and coffee, places mugs of coffee or tea, etc, in front of residents).* Here you go *(to ELAINE)*, and the sugar. And Silas, coffee, and some bread.

*JIM moves towards the stage right table to serve tea and coffee.*



ELAINE      Suffering Jesus, it's hot! Can I get a little ice to cool it down a bit?  
JIM            *(places mug of tea in front of ESME)* Esme, some tea.  
ESME        Thank you.  
ELAINE      How about that ice?  
JIM            *(turning to ELAINE)* Just leave it for a minute, it will cool. I need to get the meals.  
ELAINE      *(pushing back her chair to stand)* Let me help you there, Jim.  
ESME        Yes.

*ELAINE gently touches ESME's shoulder as she walks past, and she and JIM exit together.*

SILAS        *(having sipped his coffee, expresses in disgust)* Decaf!  
HENRY      *(with a smile, responding to SARAH's humming)* Oh Sarah, that's lovely.  
ESME        Yes!

*DOROTHY quietly adjusts her pearls.*

SILAS        Sshh!  
ELAINE      *(re-entering with something in her hand)*. Got the butter.

*ESME reaches towards ELAINE as she places a plate of butter at the stage right table, then walks to the stage left table.*

ESME        Thank you.  
ELAINE      *(sitting in her seat, newly discovers the tea with a smile)* Oh look, tea, that's nice.

*JIM enters with another cart of plates, places the cart between the tables and starts to serve to the stage left table.*

JIM            *(to ELAINE as he carefully places the meal in front of her)* Here you go. Now careful, it's hot.  
ELAINE      *(with a wink)* Just like you!  
ESME        *(laughs)* Yes!

*Everyone laughs.*

SILAS        Sshh!  
SARAH      *(turns in frustration towards SILAS)* Sshh!

*JIM moves to the stage right table to place meals.*

JIM           *(places meal)* Sarah ... There you go, Esme *(places meal)*.

*ELAINE cheekily starts scooping up large amounts of butter onto her bread.*

DOROTHY *(giggles at ELAINE)* Oh, you ...

SILAS       *(raises his finger in protest)* Jim, Jim, uh, she, she's taking all the butter, she's uh, she's taking all the ...

JIM       *(walks to stage left table)* Yes Silas, I can see that, I'll make sure there's enough for everyone. *(to ELAINE)* Now, sweetie ...

*Everyone freezes and, with heightened postures and expressions of shock, looks to JIM.*

ALL       *(dramatic intake of breath)* Gasp!

## SCENE 18 – The Interrogation

*As if undercover residents, members of the ENSEMBLE stand and clear the space, scattering like roaches, except for a chair centre stage and two INTERROGATORS.*

*JIM is pushed into the chair by one of the ENSEMBLE. Two INTERROGATORS begin their work. INTERROGATOR 1 stands facing JIM from the downstage left corner, and INTERROGATOR 2 stands facing JIM in the downstage right corner. They wait until there is stillness on stage and the whole ENSEMBLE has exited.*

INT 1       What did you say?

JIM       *(with a look of confusion, like a deer in headlights)* What?

INT 2       *(both INTERROGATORS slow and measured, begin to walk towards JIM in the chair)* What did you say?

JIM       When?

INT 1       Just now.

JIM       What do you mean?

INT 1       *(The INTERROGATORS have reached JIM in his chair and begin to circle him)* You know.

INT 2       You know what you did.

JIM       *(in his own defense)* I was asking Mrs. Carter about the butter.

BOTH       *(stop and turn sharply to look down over JIM in the chair)* No.

INT 2       You called her something.

JIM       I did?

INT 1       *(still peering down over JIM)* Don't deny it.

INT 2       *(with seething disgust)* You have violated the rights of the resident.

- INT 1        *(with increased anger and passion)* Do you know what would happen if a compliance officer overheard that?
- INT 2        *(as the ultimate punishment)* We'd get a citation.
- JIM         Oh *(breaking down under the pressure)*, OK, I, I called her sweetie. She asked me to call her that! *(cries)*

In situating these two scenes together, both in live performance and in this chapter, the stark differences between them becomes apparent. In the first scene, persons with dementia are performed as diverse, including playful, cheeky, flirtatious, agile, physically limited, musical, spiritual, shy, outgoing, scornful, frustrated, among a raft of other qualities (and it should be emphasized, each person is unique). In the second scene, persons living with dementia are merely mentioned in the abstract ("the resident"), cast in the shadow of the Interrogators more concerned with avoiding the wrath of the compliance officer in the form of a citation.

In the first scene we see a community of people living with their differences, supporting, teasing, flirting with and testing each other, getting under each other's skin. No one is performed as though an empty shell of their former self; rather, each resident gestures and expresses themselves uniquely in the present moment. We see the care-home staff member, Jim, understanding and supporting each resident's patterns and needs, knowing who prefers coffee or tea, creating space for residents to help each other and him, as Elaine does when she follows Jim to retrieve the butter from the kitchen. But audience members come to be engaged with this community of people in large part through how the actors gesture as the residents.

Sarah saunters toward her seat, humming and fiddling with her scarf; Elaine extends her arm to help Silas to his seat; Henry brings his head close to Esme's while he flirts; Dorothy gently and daintily adjusts her pearls resting on her sternum: these things are not extraneous additions to the scene to make it more visually interesting. These gestures *are the scene*, the way in which members of this community engage with each other, and the way in which audiences come to engage with the story, central to which is the importance of author Pia Kontos's theoretical notion of *embodied selfhood*. Embodied selfhood emphasizes the importance of the capacities, senses, and sociocultural dispositions of the body for self-expression, interdependence, and relationality (Kontos et al., "Citizenship"). Based on her ethnographic research in long-term care homes with persons living with dementia, she draws upon Merleau-Ponty's notion of non-representational intentionality and Bourdieu's notion of habitus to argue that despite even severe cognitive impairment, selfhood persists in and through the body (Kontos, "Ethnographic"; "Embodied"; "Rethinking"; "Alzheimer").

Contrast this with the second scene. While filled with humour, as indicated by the heightened expressions and postures of the Interrogators, the uniqueness of each resident is all but lost in this scene, which focuses on reprimanding Jim for using affectionate language – “Sweetie” – with a (nameless to the Interrogators) resident. In their admonishment of Jim, what the Interrogators overlook, of course, is the relationship among residents and between Jim and this particular resident, Elaine Carter. The gestures between them in the dining scene include gentle teasing with playful language, flirting (“[H]ot ... Just like you!”), and Elaine helping Jim with some of the serving tasks. While Jim is not a resident himself, he is invited and accepted into the community of residents by Elaine and the others in part because of his reciprocal engagement with them. Jim using the word “sweetie” toward Elaine is not out of context, especially as we learn in the interrogation scene that Jim has previously been invited to use this term by Elaine when addressing her. He uses this term to accept her invitation of being in relation. By relying on a one-size-fits-all policy that focuses more on the avoidance of disrespecting an abstract resident, the Interrogators focus their energies on also avoiding a citation from a compliance officer, thereby negating any relationship between Jim, Elaine, and the other residents.

In this way, the performed gestures of the actors as residents in the dining scene – as full human beings living in relation with each other and in place and space despite cognitive memory loss – disrupt the abstract resident referred to by the Interrogators as a nameless recipient of policy. Through the juxtaposition of these two scenes, the policy enforced by the Interrogators is exposed as absurd; not only are the Interrogators performed as absurd in their buffoonish gestures, their exaggerated walking style, and their over-exerted passion about the imposition of policy regulation, but the policy itself, as a social action that assumes residents and staff are not able to be in relation with others, also becomes exposed as absurd through its enforcement by the Interrogators.

Both scenes have received a warm reception from audience members. In performances there is often laughter in recognition of the nuances of each resident in the dining scene, a familiar chuckle in response to particular jokes (“Water tight!”), and an affectionate sigh in recognition of forgetful moments (“Oh look, tea, that’s nice”). The interrogation brings more robust laughter, and post-performance discussions have brought forth comments from audience members indicating how the scene allowed them to appreciate the absurdity of the “language police.”

However, participants from a study we conducted<sup>4</sup> exploring how audience members working in long-term care homes engaged with *Cracked* highlight the specific tensions between attending to relationships and current policy. These

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**4** | This study was funded by the Alzheimer Society of Canada Research Program.

quotations from three different participants beautifully capture the importance of being in relation with residents and following their lead, as well as the ways in which policy restricts those possibilities.

The “sweetie thing” to me was the perfect juxtaposition of institutionalized and person-centred care because institutionally, Ministry standards say that we’re not allowed to do that. And to me to do person-centred care, you kind of have to be a little more personal than that. So I find a lot of times the two battle back and forth. (Participant 1) ... when he called her sweetie and they’re going to get the compliance officer and be cited. And I’m thinking yeah. And you know sometimes you’ve got to be careful, it’s abuse and all this speaking like that. [But] really, if it comes from the heart, is it abuse? And these people – like are we all at arm’s length and cold, you know? Like, they need love. (Participant 2)

Well, like the first thing that the staff member got chastised around was “sweetie,” being called “sweetie.” And I mean, like I recognize that that can be a fine line either way. You can dehumanize someone by calling them a term they’re not comfortable with. So I recognize it can be that reality. But the flip side is often when you’re getting to know your residents, you know what works for them. And I just trust a lot of our staff that they get it, that they know what works. Here’s someone you can joke around with and that’s what they expect. If you’d be all serious with them and hands off-ish, that would not fly. (Participant 3)

Not only did study participants come to understand the absurdity of the policy they are restricted by in their daily working life but they each also understood *why* the policy might be viewed as extreme; it is extreme because it overlooks the significance of being in relation as part of being human. We would suggest that it is through the juxtaposition of the two scenes that policy is seen anew. Rules enforced by the Interrogators which might be normalized in day-to-day existence as “the ways things are” become exposed within the frame of the play precisely because audience members have witnessed positive, attentive relationships in the previous scene. Study participants reference this through language such as “you kind of have to be a little more personal than [institutional/Ministry standards],” “[residents] need love,” and the importance of “getting to know your residents.” This suggests that these participants, as people who work with residents in long-term care homes, know and live these tensions between attending to relationships with residents and policy that restricts them. However, in seeing these tensions enacted through the play, participants are provided the aesthetic space to reflect, attending to senses and emotions in addition to thoughts, and ultimately are able to voice it clearly.

## CONCLUSION

In *Cracked*, and more specifically in *The Dining Scene*, we disrupt the tragedy discourse through the ways persons with dementia are performed. Actors playing residents in a long-term care home, all living with dementia, express their characters' uniqueness through their singing, flirting, scoffing, praying, giggling, helping, and egging each other on, among other gestures. We see a lively community of people engaging with each other, including staff member Jim, who supports them and creates space for them to be themselves. Policy for its own sake, as a social action concerned with avoiding citations regarding an abstract and nameless resident, is then exposed as absurd when it is personified by two buffoonish Interrogators. It is through theatre, as an art form that attends to emotions, senses, thoughts, and actions in time and space, that an aesthetic space is created to invite audience members to reflect on how their thoughts, feelings, and senses extend to actions, including representation and policy.

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# **“Hooray for You and Me”**

## **The Story of a Theatre Group**

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*Aynsley Moorhouse*

This piece is adapted from a weekly online blog that I kept while working with a group of residents at a long-term care home. Here, we watch a group of nine older adults transform from strangers and acquaintances into an active and vibrant theatre company. We see the group members learn theatre techniques, build strong and lasting connections, support each other in their creative expressions, and work together for a common goal: to develop and ultimately perform a piece of theatre. This blog chronicles the theatre company from its first rehearsal to its final performance for approximately 200 audience members at Baycrest Health Sciences in Toronto. It showcases the power of theatre to bring great individual joy and growth, to build strong relationships and communities, and to create – even in small ways – social change.

I would like to acknowledge funding support from the Ontario Arts Council, an agency of the Government of Ontario.

## **ONE WEEK TO GO**

20 March 2012

I’m Aynsley Moorhouse, and next week I will be launching a theatre and digital storytelling program for residents of the Apotex Nursing Home at Baycrest Health Sciences in Toronto, Canada. Baycrest is an “academic health sciences centre” providing care for “older adults across a variety of institutional and community-based settings.” In their Mission, the organization states that they are “devoted to improving the quality of life of older adults everywhere through the integration and application of exceptional healthcare, wellness promotion, research, and educational activities” (Mission, Vision and Values). I am working closely with two Recreation Therapists and the Department of Culture, Arts and Innovation, and I am very thankful for this support.

My training and background is in theatre; I have an MFA in Acting from The New School in New York City, and an MA in Theatre Studies from the University of Toronto. My passion is for working with older adults and people who live with dementia. Over the last eight years I have worked as an actor, dramaturge, writer, and teaching artist with people of all ages and with varying levels of physical and cognitive abilities.

Next Wednesday, after months of programming, scheduling, researching, and recruiting residents and staff, the theatre group will hold our first rehearsal. We'll be working toward developing a devised piece<sup>1</sup> of theatre to be performed for staff and family members at Baycrest. The piece will be created collaboratively during our weekly rehearsals and in one-on-one meetings and will be constructed entirely from the participants' words, ideas, and stories. We're incorporating digital storytelling into the project: I'm going to be meeting with residents individually to make several short films about their lives. As yet, I only have a rough idea of what shape this project will take – that will depend on the interests, goals, strengths, and stories of the participants in the group.

## **AND WE'RE OFF!**

28 March 2012

Today was the official launch of the Apotex Theatre Group. I've already learned a lot! Knowing that the first day of any group project can be a bit scary and daunting for everyone (myself included), I thought it would be helpful to begin with a long introduction. I was so wrong.

My main mistake was overestimating how much I would need to ... well ... talk. I could have gone on for the whole hour (and I think I half intended to) about how excited I am about this project, about all the possibilities and my many plans, about the impact we can have, and about my training, but the people came to the group to *do* – not to sit around listening to me jabber ... about myself. So I stumbled over my words for a few minutes too many before looking up to uninterested stares. I put down my notes, got up on my feet, and shut up.

We began by discussing possible themes and topics that we could explore over the next several months. Family, loss, war, friendship, community, aging, and life in the Apotex are all themes that were brought up by the group, mostly highlighted by personal anecdotes.

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**1** | See Gray et al. in this volume, p. 111, for explanation of “devising.”

I discovered that we have a poet in the group, or rather, according to him, a former poet. His name is Barry.<sup>2</sup>

"I used to be a poet," Barry said, to which I replied, "I would love if you might try writing again, for our play." He sat for a moment without saying anything, but then, just as I was about to gently change the subject, he said quietly, "Yes. Yes, I would like that."

I should add that this is the same gentleman who, at the end of the session said to me, "I am starting to get a glimmer of interest in this project. Just a glimmer. See you next week." This left me feeling hopeful ... I think.

We also discussed what we are each hoping to gain from our time together. One woman, Fiona, said simply, "I'm here to learn how to act." Tom said, "I was a lawyer my whole life, and now I want to use my performing skills in the theatre." A woman who expressed feeling isolated said, "I would like to expand my community and get to know some of my neighbours better." Near the end of this discussion, Ned, who wants to work with me on a more directorial level, said, "I know that the people in this room have a lot to say. I want the rest of the world to know that too."

We ended the rehearsal with a brief introduction to improvisation. I started to explain how great a tool it is for generating stories and encouraging spontaneity, but again, I lost the interest of the group. So instead of talking on and on, I briefly explained the rules for the game *Fortunately/Unfortunately* so that we could give it a try. In this game, one player begins a story with the word "Fortunately." The next person adds to the story, beginning with "unfortunately ..." The next person adds, beginning with "fortunately ...," and so on.

Everyone had something rich and beautiful to add to our story. There was no plot, characters, or consistency of narrative, and I found this incredibly exciting. The urgency and enthusiasm with which each person added to the story was inspiring. It was during this game that I finally began to relax.

After the game was done, Tom gestured for the microphone (some of the participants have difficulty hearing so we use one in our rehearsals), and asked if he could do both a "fortunately" and an "unfortunately." I said, "of course!"

"Fortunately, you are wearing a lovely black sweater." I looked down at my top that has a very high neckline in front but scoops quite low in the back.

"Well thank you!"

"Unfortunately, you are wearing it backwards."

There was a pause, and then the group erupted into uncontrollable laughter. I turned the brightest red. And on that joyful and horribly embarrassing note, our first rehearsal was over.

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**2** | The names of residents have been changed in order to protect the privacy of the group members.

## THEY CAME BACK!

7 April 2012

I arrived at the second rehearsal of the Apotex Theatre Group half an hour early. When I walked in I found that Tom was already there.

He had come early because during the week he had written three pages of a script for our performance. He said that now, when he can't sleep at night, he writes. He had found a straightforward way to merge the giant topics of "life at the Apotex" and "life before the Apotex." We spoke of exploring ways in which they feed each other.

Once everyone else arrived we began talking about what will probably be a major theme of our performance – the community at the Apotex – and then Tom read his script and explained his ideas. The response from the group was supportive and enthusiastic, and we tossed around a few ideas. I think we are going to work well together.

After our discussion we dove right into some vocal acting exercises.

I was a little nervous about this. The group members – none of whom have a background in theatre – are fun and adventurous, but they are also quite serious. I am a trained actor, so I am accustomed to doing strange and sometimes playful or silly exercises, but I take them pretty seriously. I was hoping the group members would understand this and might feel the same way, but I wasn't sure they would.

I had nothing to be worried about. By joining the group, everyone seems to have made a decision to trust the process and to go along for the ride.

And boy were we LOUD!

An energy game that I brought in was also a success. Usually in this exercise the person with the "energy" makes eye contact with whoever is next to them, and then gestures with their hands (often with a clap) that they are "passing the energy" until it makes its way around the whole circle. This is how I demonstrated the exercise.

Once we started, however, a beautiful thing happened. Instead of simply making eye contact and gesturing, each person tightly grasped the hands of the person next to them as they passed the energy. This continued almost all the way around the circle. It was a joy to watch and to be a part of.

I wanted to make the idea of "our final performance" something tangible and to give the group an idea of the sort of thing we could do, so I showed a video of a scene created and performed by a theatre group at a retirement home. The scene we watched dealt with how a person's sense of identity can shift upon moving into a retirement or nursing home.

The discussion following this scene was a balanced mix of the positive and the negative. One woman said that she felt great upon arriving at Baycrest and was excited by all the arts and cultural programming. Some people talked about

the strong sense of community they have discovered. Others said that they have felt lonely since arriving. A few people who have been living here longer were able to assure some newer residents that it can take time to settle in. Everyone had something to say on this topic, and we all agreed that this group provides an effective forum for exploring both the good and the bad freely and without judgement.

## TRY US

15 April 2012

When writing about her *TimeSlips* storytelling program in *Forget Memory: Creating Better Lives for People with Dementia*, Anne Basting stresses the importance of greeting each participant individually at the beginning of every session. I've made a commitment to doing this with my group each week. It sounds so simple, but I've found it very helpful for building a rapport with group members and for ensuring that everyone feels welcome and a part of the group.

After relaxation and vocal exercises and a quick game of *Fortunately/Unfortunately*, we tried playing *The Counting Game*. In this game, a group stands or sits, usually in a circle. Anyone can call out "one" and then any other person can call out "two" and so on. If at any time two people call out a number at the same time, the counting starts at "one" again. When I play this game, the goal is usually to get to ten.

This game requires great concentration and can create a lovely sense of calm and unity within a group. I explained the rules and then asked everyone to close their eyes, relax, and for someone to call out the number "one" if and when they had the impulse to do so.

During the first round one number was called out of turn (I think we got to 4 when someone called out 7). For the next round I changed it up: "Call out any number you like. Be impulsive." And they did. 27. 14. 58. For some reason, hearing numbers called out at random like this was ... beautiful. Those of us in the room who were not participating (volunteers and one resident's granddaughter) were all moved. Something special happened when we allowed ourselves to let go of our ideas of what the game was "supposed to" be.

We spent most of our rehearsal coming up with a fictional story about someone moving into a long-term care home. We gave her a name (Marilyn), a past, and talked about her decision to move there. We talked about how she and her family members each felt about the move and why. We discussed Marilyn's fears about the move, her arrival and first day, and her conflicting emotions. We talked about her first meal, her bedroom, and her first (sleepless) night in her new bed.

This conversation went on for over half an hour. It was dynamic, detailed, and truthful. It seemed as though working with a fictional character gave everyone the freedom to discuss his or her own experiences and conflicting emotions. Everybody had something to say and it felt as though there wasn't a moment to breathe.

In the last ten minutes I asked the group if they would each share something they've learned about themselves since moving here.

Tom said that since joining our group he's discovered that he loves play-writing and that it's a great pleasure and comfort for him. Fay was very sociable before moving in but misses living alone and is having a little trouble adjusting to always having people around. Nadine had always lived a very active life and was surprised to discover how much she enjoys living quietly now. Not all of the responses were so positive. Some people have been feeling lost, and some were surprised at their own negativity.

I think the group is beginning to trust me. I shared my concern that they might think some of my acting exercises were silly. Barry responded, "Try us."

As I was cleaning up, one member's granddaughter who had sat in on our rehearsal asked if she could speak with me. She wanted to tell me how much she loved the session and was so happy to see her grandmother being part of a group like this. She thinks that this sort of model could change the types of programs that are available in nursing homes. I hope so.

## **A PLEASURE**

23 April 2012

In the last couple of weeks, members of the group have been coming forward to express how they want to be involved in our project. Tom is working on his script and is incorporating the group discussions into the text, and Ned would like to work in a directorial role. I'm sure that in the next few weeks everyone's desired roles will begin to emerge.

At our second rehearsal, Barry brought me some of his poems to read. They are beautiful. He wants to recite some in the production and has agreed to let me record him reading a few of them. Last Thursday we met to choose our favourite poems and to begin recording. In the recordings he is at times hesitant, confident, forgetful, angry with himself, and proud. He invited me over again next week so I can bring the edited versions of the poems for him to review.

For the digital storytelling aspect of the project, I will be meeting one-on-one with residents who are not members of the theatre group, to record their stories. Together we are choosing images and music which will be combined with the stories to create short films.

So far I've had three meetings with a gentleman named Edward, and I have approximately two hours of usable material for a project that is supposed to be three or four minutes in length. The stories we will use for the final product are about his time in the war and about his wife, Sophia. The recordings are full of beautiful detail, passion, and humour. His love for Sophia is clear and staggering.

Last week I ran into Edward in the main hall of the Apotex. "Hello my friend!" he called when he saw me. With him was a beautiful older woman. "This is Sophia." I squeezed her hand to say how happy I was to meet her, and she held onto my hand tightly for the whole half hour that I sat chatting with them.

Sophia doesn't say much, but her energy is amazing and it was such a pleasure to spend that time with them. We talked, they sang, and Edward told her some of the stories he had shared with me. While he spoke Sophia looked into his eyes with such trust and love. When I got up to leave, Sophia held my hand even more tightly, looked me in the eyes, and simply said, "A pleasure!"

## AC-CENT-TCHU-ATE THE POSITIVE!

1 May 2012

As usual, we began with a game of *Fortunately/Unfortunately*, and this time I asked the group members to choose a pre-determined activity and setting for the story before we got started. This is a common practice in improvisation, and can provide structure and direction for a story or scene. Nadine and Nora came up with "voting in Manitoba." Before we got going I said, "I'm from Manitoba!" to which a few people jokingly said how sorry they were. During the game some participants took the opportunity to say nice things about my home province (a province which, I should note, I love very much), but not everybody was so kind.

Tom said, "Unfortunately Manitoba feels like it's squeezed between two covers. It's got provinces on either side and doesn't have anywhere to go." Norman said, "Fortunately I live far away from Manitoba and can't go. I have many places to go before. To vote ... that's too far for me." Ned said he would hop on a plane tomorrow to go to Manitoba and vote because "it's important that everyone should vote, and I'm going to go back there for that reason."

Every week I start with breathing and relaxation and I go around lightly touching my hands to each person's shoulders and neck to aid with the relaxation. Whenever I'm in a yoga or acting class I absolutely *love* when the teacher places her hands on me to assist my relaxation or stretch. So I thought, why wouldn't I do that here? I think the need for physical contact is universal.

Before I go around I always ask the members of the group to gesture if they would not like to be touched, but so far nobody has done so. I can often feel people's shoulders relaxing with my touch.

When I introduced vocal exercises in the first week, most people participated quietly and tentatively, so I've been focusing on volume and support. Over the last month the group has been getting louder and more enthusiastic, and we are working on supporting our voices from the diaphragm rather than from the throat.

After these exercises we moved on to the *Counting Game* again, and this time right from the start I said to impulsively call out any number in any random order. Success.

Then I said, call out the numbers as though you are very angry. Then happy. Then embarrassed. The work was subtle but focused and animated, as the actors demonstrated their emotional range.

Next we played *What Are You Doing*. For this exercise, one person begins miming an action. For example, she may pretend to be brushing her teeth. Then the next person asks, "what are you doing?" and first person keeps miming that she is brushing her teeth and says a different action. For example, "I'm washing my car." The asker then begins miming washing his car, and then another person asks him, "what are you doing?" and so on. In playing this game, I discovered that the group is itching to interact with improvised dialogue – and they are really good at it. All the pairs got into a back and forth dialogue (another example of letting go of the rules), and every scene was clever – some were even laugh out loud funny.

*Nora: What are you doing?*

*Nadene: I'm putting cream on my face.*

*Nora: Lovely! Are you going out?*

*Nadene: Yes, I always like to look good.*

*Ned: Norman, what are you doing?*

*Norman: Sitting watching the group here.*

*Ned: That's very nice of you to watch the group and I hope you get a lot of pleasure from it.*

*Norman: For sure yes.*

*Ned: Ok.*

The game did not call for any dialogue. Rather, this all happened organically, and I would say out of a *need* for creative expression and interaction.

After these scenes, the group shared tactics that they use to remain positive in their day-to-day lives. Last week I had asked them to prepare for a discussion of this topic.



The responses were diverse: some were practical, some were anecdotal, and Barry's response came in the form of a song ("You've got to accentuate the positive! Eliminate the negative! ...")! Norman said, "I'm happy to come here to stay with the group and learn so much about theatre. I'm always happy to come here, close to each other." This comment speaks to Norman's desire for lifelong learning, meaningful interactions, and creative expression. These core human needs do not just disappear as we age or when we move to a long-term care home.

Fiona wasn't able to make it this week, but she left us a poem to read in response to my question. The poem is about aging, and it is positive and funny and sad and truthful and brave all at once. We discussed using the poem in the play and here's what a few people said about the poem:

*Ned: I think she's making fun of herself in her poem. In the different words that she uses. You can think of it as derogatory but it's not. It's really ... how it is today ... and how she's overcoming the thoughts that may come out in the play.*

*Barry: We're all old people and we always talk about the shape we're in, so that poem can set the tone of the play to come.*

Near the end of rehearsal, I asked everyone if they could share something about themselves that they would like the audience to know. I gave an example of a story Katherine had shared with us two weeks before, but in my retelling I got some of the details wrong. Norman and Ned immediately corrected me. Ned then elaborated, and shared his thoughts and emotions about Katherine's story, citing specific details. The people in this group are listening to each other, absorbing what is being said, and reflecting on it.

Once everyone started speaking about themselves as I'd asked, Ned took the opportunity to speak not about himself but about his Personal Support Worker whom he greatly admires. His speech was generous and passionate, and by the time he was done, the Personal Support Worker was in tears.

## **BINGO!**

8 May 2012

During our relaxation work this week, I ask everyone to begin breathing slowly and deeply, close their eyes, and imagine sitting in a peaceful place. I always give the example of a beach, and explain that during this exercise I like to imagine the way the sun feels on my body, the smell of the ocean, the sounds of the waves and the seagulls ... in other words, I ask them to imaginatively engage all of their senses.

A few of the vocal exercises we've been doing involve everyone making some funny sounds, like "ay yay yay!" and "yo ya yo ya." Before we all chanted "ga ga ga ga," I joked that we were about to make sounds like a baby, and I heard one participant say, "No way." I think she felt that making those sounds would be demeaning and I entirely understand and respect that. When we were done I mentioned that if anyone is uncomfortable with an exercise for any reason they can feel free to hold back without fear of upsetting me. I want everyone to be at ease with the work we are doing.

Because of last week's success with *What Are You Doing*, I decided to try a different improvisational game that invites back and forth banter: *First Liners*, where one person in a pair is given the opening line for a scene, and then they improvise a scene from there. As could be expected, the game was great and there were some real hits.

One example:

*Barry: I love this song.*

*Norman: Sing it to me.*

*Barry: A gaba bo daba! (Barry sings)*

*Norman: Very good!*

*Barry: I just made that up!*

*Norman: Oh – I know.*

We laugh a lot in our rehearsals now, and on three occasions someone has spontaneously broken into song.

## MEMORIES REVISITED

15 May 2012

This week while everyone was arriving for rehearsal, there was easy banter and joking about our show, our lives, our ages (I have a birthday coming up), and our families. It felt like the beginning of rehearsal for any theatre production. We've become a company.

After everyone had settled in, a few people shared longer stories about their pasts. There has been a lot of talk about a large portion of the presentation being a retrospective of the members' lives, and this has spurred much contemplation, writing, and sharing.

Fay has been particularly enthusiastic about this portion of the performance. She ran a restaurant in Toronto and has spoken about it a number of times in rehearsal. She's brought in photographs and menus and was very happy when I suggested that we meet one-on-one next week to work out a monologue about this time in her life.

This week I asked her to give us a setting for *Fortunately/Unfortunately*, and she chose the restaurant. I then asked her to begin the exercise with a "fortunately," but instead of contributing just a sentence or two she gave us the story of how her restaurant came to be.

I was delighted that she was sharing this story, but while she spoke I felt a familiar itch – the stress of knowing that an exercise isn't going as planned. It's a need to have control – and I happily just let it go. I've loved the way the exercises change depending on how the participants respond and react. This group is teaching me the important art of letting go of my plans and expectations, and I'm discovering that this is where the beauty and magic lie.

The challenge then became how to get the exercise back on track when Fay was done speaking. I did it unsuccessfully. I edited her story, and made a one-line (mis)interpretation of it. I basically made it my own. After thanking her for sharing the story, I said, "so ... fortunately we've bought a restaurant because we want to make people smile." She didn't let me take over her words like that. She answered, "I don't know anything about business! Fortunately it worked out very very well!"

So. Our story. We bought a restaurant, and even though we didn't know anything about business it worked out very well. We had a slow start because the space was small and we didn't have many customers, but the food was really good, and as people got to know us, they kept coming back for more. Unfortunately our customer base mostly only spoke Yiddish, and our staff spoke other languages, so there was a communication breakdown, but nevertheless there was constantly a lineup out the door.

We had some great scenes during *First Liners* this week:

*Nora: When life gives you lemons, make lemonade.*

*Ned: How much should I make?*

*Nora: Just enough for yourself, I don't want any.*

*Ned: Oh come on, you have to try a little bit.*

*Nora: If you mix it with vodka.*

*Ned: Vodka goes very good with it, so I'll put vodka in it for you.*

*Nora: With the vodka I'll take it. Lemonade and vodka sounds good to me.*

With just a few minutes left I checked in with the group to get some feedback on the work we are doing and to see if they had any questions or comments. Here are the responses I received:

*Ned: I like it!*

*Tom: It's damn hard work.*

*Nora: I didn't know we were going to do a production, so maybe I'm just getting used to the idea. I like coming here. We'll see what happens next.*

*Barry: I really don't know where it's going, but we'll see in the next few weeks.*

*Ned: We trust you.*

*Fiona: I think everything's great.*

*Fay: I wonder how it's all going to turn out.*

## **I'LL READ**

23 May 2012

Before rehearsal I met with Fay to work on her monologue. During our meeting I discovered that she is a poet and songwriter. Much of her work is very personal, and I'm not sure yet whether she will be willing to share anything in the performance, but I hope so. I'm learning that these one-on-one sessions are invaluable, and I will need to meet with everyone in the coming weeks. I have to admit, this is a much larger project than I ever would have imagined.

*Fortunately/Unfortunately* went around the circle twice this week – not at my urging, but simply because the story just kept on going: “Fortunately a very beautiful girl married a very handsome man.” Unfortunately, according to Tom, “he was already married.” Not to worry, they got married anyway. Of course, there were “consequences” on their first night together, according to Fay, but “fortunately they had got a good lawyer who straightened them out,” said Fiona. Unfortunately, continued Katherine, “the handsome man had a pimple on his chin.” But fortunately the pharmacy was open and he could get some “depimping” ointment. But, added Nora, if she really loved him, the pimple wasn’t going to make that much of a difference. “What’s a pimple?” concluded Katherine diplomatically, giving the story the final word.

After our relaxation and vocal exercises we did some choral speaking, using the poem that Fiona brought us a few weeks ago, and we worked on technique, subtext, and expression. I had always assumed that when the speaker in the poem says that she “is feeling fine,” she says so in earnest, but the group disagreed with me, saying that this line should be read with cynicism. With this simple choice, the poem has more of an arc, and tells a more compelling story.

For the last twenty minutes we read a portion of Tom’s play. I gave copies of the script to Tom and to two other women who had expressed interest in reading it. We needed one more actor, and I asked the group if there was anyone else who would be willing to read a part. There were no responses.

“Nora,” I said, “would you like to read it or would you rather I did it?”

“No, it’s ok,” she replied.

“Oh ok, that’s fine,” I said, thinking she meant that she didn’t want to read and not wanting to push. Nora was hesitant about joining the group in the beginning, and I have been so happy to have her come in and participate each week.

"I'll read," she said. My heart leapt.

So, for the next twenty minutes, four members of the Apotex Theatre Group did a cold reading of a brand new play written by one of our members. Everyone – staff, volunteers, and group members – was blown away.

After discussing the play, Nora said angrily, "Can I please say something?" I was worried. She continued, smiling mischievously: "Last week you told us your birthday was coming up and I think you said it was today, but we forgot to wish you a happy birthday."

I hated telling her it was next week, but said I was so happy that she remembered. "Yes, I remembered," she replied with a smile. And with that, we all said our goodbyes and left for the day.

## BREATHE

29 May 2012

This week I had two minor setbacks. One involved a new digital storytelling participant expressing concerns about sharing her story publicly; the other involved someone being uncomfortable and unhappy with the sound of his voice on a digital recording.

I was feeling defeated. Luckily, on my way out of the building, I got a chance to speak with Bianca Stern, who leads the Culture, Arts & Innovation Department at Baycrest. I told her what had happened. She gave me some really sound advice.

First: Breathe.

Second, she reminded me that these individuals are putting themselves and their stories out there in a way that many of them never have done before, and that of course they are going to feel vulnerable and scared sometimes. All I can do is respect that and be sensitive to their reactions.

She suggested finding ways to ensure that the new participant feels that she is in control of the recordings and has agency over her stories, and suggested ways of making the other person more familiar with the sound of his voice. As anyone who has heard their voice on a recording knows, it sounds very different than it sounds in your head. It can be disconcerting to anyone.

Most importantly for me, she told me not to take these reactions personally. Just breathe.

This week the group surprised me with a little birthday party! It was wonderful. We all got cake and everyone sang *Happy Birthday*. I was so happy.

By the time we were done partying it was almost time to go, so we did some choral speaking, chatted a little, and then said our goodbyes.

Until next week!

## WHY ELSE WOULD I COME?

5 June 2012

Rehearsal was great this week. *Fortunately/Unfortunately* was funny and animated as usual; we played *First Liners* again; and we played *One Word Story* for the first time (similar to *One Sentence Story*, but each participant contributes just one word to create the group story). People sometimes contributed just a word, but often added a whole phrase or just a sound. It worked beautifully, quickly, and with incredible momentum:

*I have a dog.  
Once upon a  
time  
poor animal  
dog,  
dogs are good.  
bow!  
wow!  
Cat  
meow  
Afraid  
I don't like cats  
Or  
Anybody else  
Jump  
High!  
Don't fall  
Can't escape  
Or  
Or injure my nape  
Went out  
For fun  
I laugh  
My dog does too  
Or  
Or he thinks he does!  
I smile  
My dog giggles  
And  
I don't believe it  
Or  
He takes Setlas Powders.*

*Come over and see it!*  
*Right!*  
*What time can you make it?*  
*Very early in the morning*  
*Seven*  
*The dogs have been out chasing cats all night*  
*It's too late!*  
*It's never too late.*  
*Call the dog in.*  
*He doesn't like that!*  
*Or*  
*He doesn't like being called.*  
*I'll tell you something else:*  
*He chases the cat.*  
*Happy days are here-*  
*Not with dogs and cats.*  
*Again.*  
*End of story.*

I recovered from last week's setbacks, but I left this week's rehearsal with some doubts raised by the group members about whether or not we can pull this off. I know these doubts are unfounded ... but there's still a little voice in my head that says, *what if we can't?*

One question that was brought up was why we've been playing improv games every week when we are supposed to be preparing for a performance. I should have explained this to the group earlier. *I* know that we're warming up our imaginations, learning performance techniques, breaking down inhibitions, and getting creative. We're exploring our impulses, and getting to know each other's. We're building a company. To me, the link to the performance is clear, but it wouldn't be as clear to the group members.

The digital aspect of the project is taking much more time than I had anticipated, and I'm experiencing some setbacks. One of my participants was happy to share her stories with me but didn't want anything to be recorded. I understand entirely, and we spent a lovely hour together, telling each other stories of our lives. Another woman has agreed to make a digital story, but she is nervous and doesn't know whether to trust me or not. She has said that she's not sure that she will like the piece in the end, and I've told her that if she does not want the piece to be shared, it won't be.

I keep telling myself that all I can do is try, and know that the process of creating the piece is just as important as the product.

I need to *\*breathe\** and remain focused on all of the positives.

For instance, the theatre group members are becoming more ambitious, creative, and animated while in rehearsal, and they have all told me that they enjoy coming.

Also, some friendships have developed between people who met in the group! Katherine and Norman often joke together affectionately, and this week they did a little hula dance together during a luau in *Fortunately/Unfortunately*. When it was her turn to speak, Katherine said, “Unfortunately Norman wasn’t in Honolulu with us!” Then she sighed, “Oh Norman. My Norman.”

After rehearsal one day, Barry was going to go outside to enjoy the sun, and Nora said that she would like to join him. Barry replied that he would be delighted. Smiling, Nora turned to me and said, “we seem to enjoy each other very much. I just met him here.” Barry agreed with her, and then she continued, “It’s just nice talking to someone who you enjoy.” She then said, “I sort of feel like we’re here to get to know each other. Before I got here I didn’t know any of these people ...”

At the end of the day, we’re here for the experience of getting to know each other, and hopefully, for our audience to get to know us a little too. We’re here to explore a new skill set, to have fun, to exercise different parts of our brains, to be creative, and to be heard.

## **QUALITY OVER QUANTITY**

12 June 2012

Over the last few weeks, Tom and I have been editing his script, and he gave me permission to do some cutting and reorganizing on my own. So I shortened it to what I thought would be a manageable length and brought the script to rehearsal this week for a full cast read-through.

Tom was a little disappointed with some of the cuts that I had made, and I felt quite badly. Each part of this play is precious and meaningful to him, and he’s been up late many nights working on it. It can be difficult and unnerving to work with an editor or dramaturge, and maybe it would be best for us to do any major cuts together from now on. I don’t want to run the risk of taking ownership of it.

Earlier this week I called a meeting with the two Recreation Therapists who I’ve been working with to get a sense of how they think the program is going so far. They assured me that so far it’s been a great success, and gave me some advice. They said that the participants are keen to have a sense of how the final project will look, and suggested that the best way to address this would be to help the participants see the project visually.

So next week I’m going to bring in a giant roll of paper, so we can make a timeline of the one-hour performance. As a group, we’ll come up with the order



of events. The suggestion was to be as specific as possible and plan it down to minute detail.

The other big piece of advice was to focus our rehearsals entirely on the show from now on. This means no more *Fortunately/Unfortunately* or improv games, and it means having just a short and precise warm-up period.

I've decided that, moving forward, I will only be working with the theatre group members to create the digital storytelling aspect of the project, rather than recruiting other residents as I had originally planned. I think I expected everyone to trust me immediately and to jump at the opportunity to tell me all of their personal stories. As I've mentioned, that has not always been the case. The members of the theatre group have already had time to learn to trust me, and they are keen to share their stories.

## GROUNDWORK

18 June 2012

Today we created our visual timeline of the performance. This is what we came up with:

Seven of the nine members will be doing monologues. Tom isn't doing one because he feels that his stories are best told in the play he wrote, and Ned is participating in the group as a director rather than as a performer. He has said on numerous occasions that he is interested in helping others tell their stories rather than in telling his own.

About half of the participants have already written a monologue, and the others will have theirs finished by the end of June. I've met with everyone privately at least once to work on these, and I hope to create digital stories with each participant in addition to developing the live monologues.

We will then read the poem that Fiona brought in, and will end our performance with Tom's play. Tom is comfortable with doing an excerpt of it rather than trying to cut down the whole play, and we will have printed copies of the full play for audience members to pick up on their way out.

The digital components of the performance will happen sporadically throughout the hour. These are: three of Barry's poems and Edward's digital story.

We've decided that the actors will have their scripts on stage with them, as we don't want to worry about memorization. There are two actors who have visual impairments, so we will need to come up with a solution for them.

After making the timeline we still had fifteen minutes of rehearsal left, so I took everyone through a quick physical and vocal warm-up, and then we practiced our choral speaking with Fiona's poem. When we were done going through it once, Barry said, "That sounded pretty ragged."

He wasn't lying. I'm hoping we can rehearse it enough with everyone speaking in unison, but if it doesn't work, we'll have to come up with something else. We'll see what happens.

## **HOORAY FOR HOLLYWOOD!**

26 June 2012

There are only five rehearsals left until our performance, and – as luck would have it – we had to cancel our rehearsal this week. In fact, all programs were cancelled because there was an illness going around on our floor, and the people who live on that floor were unable to meet with me.

Three participants who live in a different area were still able to meet.

A major piece of business we discussed was creating a title for our performance. Katherine came up with, "Hooray for Hollywood!" Ned loved that, suggesting that "Hooray for You and Me!" may be more appropriate for our group. We then added the subtitle, "An Evening of Theatre."

I have been concerned about Ned having enough to do for the final performance, because although he has a directorial role in the group, I really would like him to be on stage. This week he voiced that he would like to introduce the performance to the audience.

At one of our first rehearsals he had said, "I know that the people in this room have a lot to say, and I want the rest of the world to know that too." His words to the audience will, no doubt, be very powerful.

I have also been concerned that those participants who have visual impairments wouldn't be able to read a monologue on stage, but we're beginning to solve that problem too.

When Nadine and I met one-on-one last week, we wrote her story out, chose a few key points which she memorized, and practiced a few times. Now she is able to improvise the whole thing while hitting those key points. We've come up with a few questions that I ask her to move her onto the next point.

My fingers are crossed that programs are back on next week, and that the group will be able to meet.

## **TWO MORE WEEKS AWAY**

10 July 2012

Well, our last rehearsal *was* in fact cancelled due to the illness, and then to top it all off, I had to travel home this past week to visit my family. So ... our group hasn't met in almost a month.

I feel good about where we are, but I'm anxious to get the group back together again. Instead of the rehearsal, I had some one-on-ones. I met with Nora to finalize her monologue. She has expressed concerns to me over the last few months that her stories aren't interesting, but if only she knew! Her monologue is terribly charming and touching – it's the story of how she and her husband met and fell in love as teenagers ... I don't want to give too much away, but I'll just say that it includes some confessions about breaking the rules at a summer sleep-away camp.

With just a month left, I've had a lot of planning to do, so most of my time has been spent on coordinating the performance, publicity, technical requirements, organizing a reception, et cetera. In order to ensure that I keep on top of all of this while mostly focusing on the artistic side of the project, I've brought a Production Assistant on board.

Our assistant, Grace Smith, is working on her PhD in theatre, and is a playwright, director, and dramaturge. I'm really looking forward to working with her.

Until next week!

## AND ... WE'RE BACK!

17 July 2012

Our first rehearsal back was really productive – we fired through everything we needed to accomplish. I think everyone feels that since we lost so much time we've really got to hustle. There is a buzz in the air nowadays!

We quickly went over the schedule of events for the performance, did some warm ups, and then went right into working on our choral speaking.

After some humming and hawing we decided to try having each person recite two lines on their own, one after the other. It sounded and looked amazing. We all agreed that we preferred it this way. Not only does it sound clearer, but each actor has a chance to showcase their expression and acting skills. It's also quite neat to see how each person approaches the text differently.

A few people shared their monologues, and then we went through Tom's play, *Changing Your Lifestyle*. Since I hadn't been able to meet with Tom in such a long time, I had to make an executive decision on which sections of the play will be read during the performance. Almost everyone was happy with the reading and with the sections that I chose. Most importantly, Tom was very pleased.

As we were leaving, I told the group about the private reception that will follow the final performance – it's a reception just for us – and everyone was

delighted. We will have a champagne toast with petit fours, and lots of hugs and tears and goodbyes, I am sure.

Then Fiona expressed a concern, asking, “What will we do with all the people who came to see us perform? Will we just kick them out?” She’s right, this may be a problem. The audience members will most certainly want to spend time with us after the show.

Katherine said, “We’ll just say ... ‘Au Revoir!’”

Problem solved.

When I met one-on-one with Fay the next day, she told me that she had been practicing her part of the poem on her own. She recited her two lines for me, and her dedication to the meaning behind the words and the pride that she took in the performance of it was just beautiful. I am so happy to share that she has decided that she will sing one of her songs in the performance. Just two months ago she was not willing to do so, and I am so glad that she changed her mind. This is a brave decision, and it will make a powerful addition to the show.

## **THREE WEEKS TO GO!**

24 July 2012

We had another really productive rehearsal and managed to get through the first half of the performance, which includes all of the monologues, and everyone was pleased. I think it was good for us to have a more concrete sense of what the evening will actually look like.

I’ve had a few one-on-ones with Barry to help him memorize his section of the group poem, as he has visual impairments and will not be able to read the words. During our meeting I gave him a direction that must have seemed detached from the rest of the poem. He thought for a minute, and then responded by saying, “Yes, but I’m part of a whole, right? I need to be aware of and respond to what the people around me are doing on their lines too.” We are each a part of a whole, here, and none of us could do this alone.

We are all working really hard, and everyone is dedicated to the performance. Nora has a very quiet voice but is making a pointed effort to speak loudly. Even Barry commented on her improvement. Fay and Fiona are practising a lot on their own. Tom has told his whole family about the performance, and it looks as though they will all be coming. Barry is also expecting a large crowd – he asked for twelve invitations (I was expecting to give everyone four or five!).

Three weeks to go.

## SHARE THE JOY

31 July 2012

This week we had our best rehearsal yet. And it was the first time I realized that, with only two and a half weeks until the show, I am going to be so sad when it is all over. I think a lot of people in the group will be, too. We've become quite close.

We read the play twice, and I couldn't believe how well this went. Then, with ten minutes left, we read through our group poem and, like the play reading, it was fantastic. My only directions were, "Be energetic! Be loud! Listen to everyone else when they speak!" The two people who had to memorize their lines did so with no problems and picked up their cues without delay.

My one-on-ones were so nice this week too. Fiona and Barry both told me how much fun they are having, and how much they enjoy the group and our one-on-one time together. Then, when I was meeting with Norman and told him I had to go meet with Ned, he said, "Yes, go share the joy."

## SIX DAYS TIL SHOWTIME!

8 August 2012

We're almost there! And we are ready.

One thing I'm finding really interesting throughout this process is watching the different ways the actors are working. Vocal technique comes really easily to some people while others have to work especially hard to speak loudly and clearly. The people who struggle more have been working incredibly hard, and it's amazing to see their effort and determination. I think it's actually visible in the work.

What is also amazing is the support they all show for each other. Those who haven't been struggling as much keep mentioning with awe how much the others are improving, and those who have been struggling often say how much they admire the others' work.

After a read-through of the play, we talked about whether we want to have a talkback at the end of the performance. I would like to have one, so the audience can have a chance to speak directly to the group members about the process. So far, any observations about the group have been filtered through my voice.

One of the Recreation Therapists turned to the group and said, "Let me give you an example of a question someone might ask: Have you been enjoying the theatre group?" There was an instant response from the group. "Oh yeah!" "Yes!" "Of course!" And then we asked everyone to be specific about what they have enjoyed. People talked about meeting new people and becoming friends, about trying something very different and challenging, and about hearing each

other's life stories. Then Norman turned to me and pointed. "We like *her!*" he said, with a big smile on his face.

We then talked about the post-show reception and a few people voiced that they want to be able to invite friends and family. I completely agree: it would be really hard to kick everyone out right after the show. We were trying to cut down on costs, but it wouldn't be worth it.

The Recreation Therapist began asking questions because she is organizing the food. I said something dismissive like, "Oh, don't worry! It will work out ... we'll just get a bit more." Then I laughed because I realized how unhelpful that was. We were all laughing and Tom raised his hand and waved at me to come over with the microphone. He looked at the group and said, "The fairy godmother will bring the cookies!"

After deciding to double our food order, we all said goodbye. One rehearsal left!

## **It's SHOWTIME!**

12 August 2012

One more day! I can't believe it.

I have so many butterflies in my stomach about tomorrow and Tuesday, but I know it is going to be a beautiful show. I won't leave many details of our last rehearsal here just now, because of course it went very well – and I need to get back to getting ready for the big show.

## **WE DID IT!**

21 August 2012

I am finding it difficult to put into words the full experience of what has happened over the last five months since the group has been meeting, and especially over the last few weeks leading up to the performance. It has been amazing. Terrifying. Exciting. Moving. Hilarious. Unnerving. Inspiring.

At the beginning, many group members expressed doubts about the group itself, but they kept returning week after week and said they were intrigued and were having a great time. Almost everyone expressed concerns and doubts about our ability to create a finished product, even up to 3 weeks before the performance.

I really can't express how much the people in the group have changed and grown over the last five months. I took videos of almost all the rehearsals, so I have been able to roughly track the group's progress and conduct a qualitative analysis of the effectiveness of the program. I also checked in with participants

throughout the process to find out how they felt about the whole thing. The results have been astonishing. It is so neat to see nine people in their 80s and 90s *excited*.

On the days of the performances, so much of what I saw and heard from the group members was reminiscent of how I felt as an emerging young actress. Being on stage is an intangible experience, and it's why so many people get drawn into the theatre, in spite of the poor odds of ever being able to live above the poverty line and in spite of the constant struggle. The people in this group got to experience this feeling for the very first time, so late in life.

Close friendships and intimate bonds were the facets of theatre that I loved the most as a young actress, and I saw them replicated here at Baycrest. An invaluable outcome of this project has been the connections that were built between group members, the larger Baycrest community, and, I think, beyond. Before the show, the group members were all laughing and talking together easily, and making jokes with each other. Many group members have commented repeatedly on the friendships they have made in the group, with people they had never even met before.

Over the two performances we had between 150 and 200 audience members. It was incredible – and the performers blew everyone away. One audience member, also a Baycrest resident, approached one of the group members a couple days after the show to say how much she loved the performance and how moved she was by it. The actor invited her over to her room later that day so they could talk about it.

Another resident who declined joining the group told me, right after the show, that when he first heard about it he thought it was going to be silly, and he didn't want to have anything to do with it. After watching the production, he had to tell me how wrong he was, and how amazing it was to see these people express and create with such dignity and power.

On our first day back in March, as he was leaving, Barry had said to me, "I am starting to get a glimmer of interest in the project. Just a glimmer." Then just yesterday he said with incredible emotion, "We were just a bunch of ordinary people, there was nothing special or extraordinary about us. I mean, we weren't actors ... And you took us ... you got us all together and now look at us!"

Nadine has said to me a number of times that she would like to keep the group going, because with her vision and hearing problems, engaging is difficult for her. She felt that this was a stimulating and fun experience, and really hopes that it continues. Everyone is really sad that it is over, and they want to keep meeting. I do too. Nora has said that she doesn't know what she's going to do with her Wednesday afternoons. "They're so boring now," she says. Ned has said the same thing. It was very hard to say goodbye.

So for now, I will just say: *Au Revoir!*

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**Part 3:**  
**Literary and Cultural Perspectives**



Betsy Struthers

## MY MOTHER DEFINES PURGATORY

Wakes, or at least thinks she wakes. Sniffs, expecting mahogany, black earth, gets a whiff of lemon polish, an outhouse door left open. On her back, arms at her sides, not wrapped around her husband – *where is he?* Flexes fingers, toes, ankles, elbows – joints respond the way they should do. Rubs one palm down her thigh, slick of a nylon nightgown. Once, on her honeymoon, she slept in pink satin.

Opens her eyes. Gray square a window in the wrong place, wrong shape to be her room at home. Too much stuff – wardrobe, armchair, bookshelf – too many pictures on the walls, all white borders, black frames – oh, family photos, her children and grandchildren. How can she be as old as her own mother? Feels the weight of her infants in her arms.

Knock, knock – door opens before she can ask *who's there?* Squeak of soles, rough hands, a soft voice urging *get up now, it's time to get up*. Sheet pulled off and the stink of pee, a baby's wet the bed. Can't they hear the baby crying?

Half carried, half pulled into a bathroom. Light too bright, rods bracketing the toilet. A sink. No tub, no shower. Shivers when the gown's stripped off, folds her arms across her single breast. The scar aches. Heart hammering.

Tugged and heaved and a diaper pulled up between her legs. Finally, allowed to sink back into bed, though it's too hard and barred just like a crib. Sheets frosty cold and stiff, stink of a chemical that mimics drying on the line. She always dried her sheets out on the line. Where is she now? A hospital? A prison?

Lies flat on her back, stares at shadows pulsing on the ceiling. A thread of light under the door now shut. Straightens her legs, feet arched against the cramps. Folds one hand on the other, palms flat against her chest, feels it rise and fall with each sighed and stubborn breath. Eyes closed, counts sheep. Wills her body to be still. To be prepared. Practicing for death.



# The Third Age in the Third World

## Outsourcing and Outrunning Old Age

### to *The Best Exotic Marigold Hotel*

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Amanda Ciafone

When the proprietor of the Best Exotic Marigold Hotel for the Elderly and Beautiful, Sonny Kapoor, hyperbolizes his goal “to create a home for the elderly so wonderful that they will simply refuse to die” immediately after the death of one of his residents, he is a comical Third World tout selling his care home through fantasy. But the fantasy of *The Best Exotic Marigold Hotel* (BEMH) is more powerful, as the movie presents a vision of distributing the Global North’s presumed burden of caring for older people to other parts of the world; in the process, it reimagines those older people as being able to take care of themselves. The radical difference of the Indian care home portrayed in the film sets the stage for a comparative normalization of its elderly British protagonists and an opportunity for them to demonstrate characteristics most celebrated in contemporary societies and economies through their encounter with otherness.

These films are not alone in representing old age abroad; indeed, “old-age migration” appears to be increasing, both in media representations and in actual practice.<sup>1</sup> With the popular press reporting on an impending demographic and economic crisis in the developed world, as they often frame the increasing population over the age of 65 and the strains on health care, social welfare, and long-term care systems as well as national economies, there are increasing mentions of older people moving abroad for old age and its associated care.

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**1** | Thank you to Jonothan Lewis for his research assistance for this chapter. In addition to BEMH and its sequel, *The Second Best Exotic Marigold Hotel* (2ndBEMH), other texts tell similar stories about the adaptability, resourcefulness, and vitality of older people as they construct a Third Age through an encounter with difference in the Third World. On the small screen, reality TV – including a BBC miniseries inspired by the films, *The Real Marigold Hotel* (2016–present), and *House Hunters International* (2006–present) in North America (internationally on the Travel Channel), – has presented such narratives.

These decisions seem to be motivated by economic concerns—concerns that private and public pensions, national health-care plans and personal savings will be underfunded or insufficient to support an established standard of living or, at the least, a decent old age. Persistent inequality between regions of the world means that older people’s purses of pounds, euros, yen, won or dollars may feel strained in their home countries but have impressive purchasing power in developing economies. Communications and transportation technologies allow greater interconnection across distance, while the legacies of colonialism and contemporary transnational consumption (of international goods, tourism, etc.), discourses of global cosmopolitanism, and assumptions of the free flow across borders for the privileged empower Global North citizens to imagine an old age abroad.<sup>2</sup> As a result, a significant number of people are moving from the Global North – thus becoming “old-age migrants” – to warmer, more affordable locations for retirement and care in old age (Ackers and Dwyer; Banks; Casado-Díaz et al.; Croucher; Gustafson; O’Reilly; Huber and O’Reilly; Warnes and Patterson; King et al.; O. Morales; Dixon et al.; Ibarra; Toyota and Xiang; Horn et al.; Horn and Schweppe).

As aging studies scholars and critical gerontologists point out, in a time when Global North countries frame aging as a crisis, with concern about social security, health care, and long-term care systems collapsing under the weight of a large aging population, other social, cultural, and academic discourses have reconceived the non-frail old in an “active aging” paradigm, constituting them as the “new elderly” and the “young-old” in the “Third Age” and hailing them as active and productive contributors to society and economy (van Dyk, “Appraisal” 93). Active aging principles attempt to acknowledge and empower older people, but they also reproduce classist, racist, sexist, ableist, and even ageist assumptions in the definition of who and what is deemed appropriately “active.” Active aging logics also serve an ideological function in the context of neoliberalism, enabling the restructuring and retreat of the welfare state and the privatization and outsourcing of the maintenance of old age onto old people themselves, who are reimagined as resourceful, flexible, creative, and economically generative in terms acceptable to contemporary capitalism (Cruikshank; Holstein and Minkler; Katz and Calasanti; Katz, “Growing”; Katz, “Busy”; Laliberte Rudman; Marshall; van Dyk, “Appraisal”).

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**2** | This chapter focuses specifically on old-age migrants from developed countries who have had little previous interaction (touristic or brief) with the less-developed countries to which they are relocating. There are growing bodies of literature studying immigrants to developed countries returning to their countries of birth for old age as well as the transnational migration of older people to the Global North to serve as care providers themselves (for grandchildren, etc.).

In this context, *The Best Exotic Marigold Hotel* and its sequel, *The Second Best Exotic Marigold Hotel*, present fantasies of simultaneously outsourcing the costs of economic, physical, and emotional care to other societies and, for older people, outrunning the limitations of aging conceived in the Global North by encountering difference in order to prove the older characters' mobility, adaptability, risk-taking behaviour, and entrepreneurial productivity, the very qualities that define their neoliberal subjectivity and justify potential cuts to governmental support. Texts like the *BEMH* films thus help construct a Third Age through an encounter with difference in the Third World.

### **“OUTSOURCING OLD AGE. IT’S A BRILLIANT IDEA.”**

*BEMH*'s primarily North American and European audiences need little reason to take seriously the prospect of British characters moving halfway around the world to a care home in India, so accustomed is the audience to the many arguments that Global North societies are facing a demographic “crisis” that requires solutions both on the scale of the individual retiree and society more broadly. Similarly, the idea that enterprising young businessman Sonny would see these population shifts and the various societal failures to meet their challenges and attempt to capitalize on his country's lower cost of living by creating a care home to “outsource old age” to India seems to make good global capitalist sense to viewers trained in accepting the worthiness of profit maximization. Sonny markets not only the Best Exotic Marigold Hotel's postcolonial affordability but also its “proud tradition of the Raj,” in an orientalist appeal to white Brits of a certain age. Therefore, within the first minutes of the film, each of the British protagonists' reasons for setting off have been presented in quick succession, and they are arriving at the airport and embarking upon the fantasies of their new lives in India.

“Outsourcing” is the overarching conceit of *BEMH*, and the resulting challenges and possibilities of connecting across cultural difference are the main drivers of character development and plot. In the very first moments of the film, before we even see Evelyn (Judi Dench), we sense her frustrated disconnection as she tries to make sense of her Internet connection and have a phone conversation with a presumably outsourced Indian call-center worker who speaks from a script rather than empathetically engage with her over the death of her husband. Moments later, as the film introduces Muriel (Maggie Smith), it also paints Global North social-welfare systems as overburdened and expensive, and those not able to adapt to international capitalist fixes as antiquated and racist. The British National Health Service offers Muriel a painful six-month wait for costly hip surgery, or the alternative of becoming a medical tourist “outsource[d] ... to another hospital where they can perform the surgery almost

immediately and at a fraction of the cost.” It is not, as xenophobic Muriel fears, “local.”

But the clearest statement of the outsourcing fantasy of the film comes from the comical but loveable proprietor of the Best Exotic Marigold Hotel for the Elderly and Beautiful, the young Sonny (Dev Patel), who states his business plan plainly, explaining to his mother how he will make his “fortune”: “I have a dream, Mummyji. A most brilliant one. To outsource old age. And it is not just for the British. There are many other countries where they don’t like old people too.” This is a moment of levity, but the piquant laughter comes from conveying a painful kernel of truth. By the film’s sequel, not only has the original film’s conceit been proven (extradiegetically) successful enough to financially justify the production of a second film, but also, within the world of the film, Sonny’s business plan has been vindicated, with both Indian and foreign investors interested in capitalizing on the transnational old-age market. As his rival Kushal (Shazad Latif) says of the need not only to continue but also to expand: “Outsourcing old age. It’s a brilliant idea. It’s brilliant and it’s working, but to keep growing, you’ve got to have somewhere to grow into.”

*2ndBEMH* thus goes even further than *BEMH*, which portrays old-age migration to India as an economic solution for its older English characters to live well on meager retirement savings, by representing old-age migration to India as an economic solution for transnational capital as well. The sequel positions viewers not only to root for transnational capital as the future of the hotel but also to be in awe of it, as it displays an almost metaphysical power in the lives of the film’s characters. The film opens with scenes of Sonny, accompanied by assistant manager Muriel, selling their business plan to an American multinational senior-living corporation in an attempt to become its first Indian franchise and receive an infusion of foreign capital to support their proposed expansion. The film’s plot then revolves around unmasking the corporation’s secret reviewer, with the film asserting the imperative that he or she be impressed upon to recommend investment. This representative of US capital turns out to be Guy (Richard Gere), who finds not only a match for his corporation’s interests but also, in melodramatic style, a love match for himself in Sonny’s widowed mother. As the film closes, it is none other than the CEO of the multinational senior-living corporation (David Strathairn) who suddenly materializes as the audience contemplates Muriel’s foreshadowed impending death. With a calm, omniscient presence, he explains he is there “to pay [his] respects,” revealing he somehow knows she will soon die, as she questions him with both deep trepidation and deference, “What are you doing here? ... Why, why did you come here really?” He is a reassuring angel of death whose gaze lingers on Muriel as the scene cuts to the next morning when she, separate again from her English compatriots now each paired off in their romantic couples riding into the future, looks out onto her own fateful next moments.



## THE THIRD AGE IN THE THIRD WORLD

Aging studies scholars, applying postcolonial studies approaches to aging, have argued that in the developed world the elderly have been treated culturally, socially, and politically as “others,” even “subalterns” (Kunow; van Dyk, “Othering”). As Kunow argues, old people have been “selectively identifi[ed] as] a group of people whose age made them different from the rest of the population and positioned them as an object of government policies” (104). While public pension, health-care, and welfare systems cared for aged bodies and protected older people from poverty, they also constructed old people as objects of governance, acted upon but disempowered to act, thus subalterns removed from social, cultural, and political participation. But in the recent decades of neoliberal politics, the governance of old people itself has come under threat, such that the “subalternity of senior citizens has by now become increasingly precarious,” citing Estes and Phillipson: ‘If welfare and social security provision created [...] a new identity for old age, it is precisely the transformation of these institutions that has posed a major challenge to the position of old people’” (281, qtd. in Kunow 104; ellipsis in original). Elderly populations are perceived as a public burden, living longer, growing in demographic size, using more public resources, and not contributing to the economic productivity of the new economy, with neoliberal politics framing an intergenerational conflict over resources, motivating proposed cuts to social-welfare systems. Further enabling the reduced support and governance, older people are being culturally reframed and remade as neoliberal agents rather than others.

*BEMH* challenges the othering of old age by asserting the similarity of its older protagonists with younger generations and the qualities of neoliberal citizenship celebrated by contemporary societies and economies. As Madge (Celia Imrie) humorously and didactically states, “I don’t want to grow older. I don’t want to be condescended to. To become marginalized and ignored by society. I don’t want to be the first person they let off the plane in a hostage crisis.” *BEMH* does this normalization work by setting old age in comparison to a people, culture, and locale represented as even more foreign and peripheral to the experience of the assumed viewers – actual postcolonial subalternity – thus making old age relatable and comparatively central or “normal.” Beyond this comparative frame, the old people in *BEMH* shed their otherness through their encounter with India and “the unsettling experience of exposure to otherness” (Gilroy 69). As life in India is presented as an “assault on the senses” and a challenge for the characters to overcome, the older characters demonstrate their potential personal development in later life, affirming the logic of “active aging,” in this case by actively aging by engaging with difference. *BEMH* thus assumes a white, Western, and multigenerational audience whose ethnographic gaze is “fixed on the edge of a space looking in and/or down upon

what is other” (Pratt 32), both Indians and old people, in the hopes that they can be impressed by both the radical difference of the Indian context to provide challenges for the older main characters and their ability to overcome those challenges by demonstrating characteristics generally associated with youth and the neoliberal economy, such as mobility, flexibility, resourcefulness, and risk-taking.

In celebrating the assertion of the active aging paradigm that old age is best lived by facing new challenges the film validates the global mobility of the white British principals who move across borders to be empowered by the challenges they face in India. But this mobility is rooted in geopolitical privilege; even if they are economically strapped in the context of their British native home, they have the comparative cultural, financial, and racial capital to choose to migrate and succeed in reestablishing themselves in India. Karan Mahajan, one of the few Indian writers to review the first film, tersely entitled it “Eat Pray Die,” drawing attention to the orientalist, touristic pretense of the British characters’ appropriation of India for their senior identity remaking and adventures. India is coded as an exotic, liminal contact zone where British protagonists can construct their identities in relation to the encounter with the other in a process that is mutual but dramatically imbalanced in power (Said; Pratt).

Donning dupattas, riding in rickshaws, doing yoga at daybreak, the English characters demonstrate their adoption of Indian cultural life and their worthiness through adaptation, their ability to be flexible, mobile citizens with youthful openness to change and risk taking. *BEMH* celebrates the cultural adaptation of most of its main characters and denigrates those who resist embracing their Indian existence. Evelyn proves her independence after years of relying on her now-deceased husband, braving unknown streets and communicating across linguistic and cultural difference, even sparking a professional life for the first time by teaching a group of sales-focused call-center workers how to speak humanely to elderly British customers. Douglas (Bill Nighy) develops new interests in Indian history, exploring sites around the area, and demonstrates unknown resourcefulness in fixing up his broken-down Indian motorbike and hotel-room tap. Madge and Norman (Ronald Pickup) find a new terrain of Indian dignitaries and descendants of British colonial society to conquer sexually. And, most dramatically and pedagogically, Muriel is able to change from a virulent racist—fearful, resentful, and hateful toward the Indians around her—into a permanent resident who loves and is loved by her Indian caregivers and eventual co-workers. As Evelyn concludes in her voiceover reading of her blog, which narrates the first film and is itself a technological demonstration of her adaptability since at the start of the film she was not even clear about how to get online: “the person who risks nothing ... does nothing, has nothing. All we know about the future is that it will be different. But perhaps what we fear is that it will be the same. So we must celebrate the changes.” The social-

climbing snob Jean (Penelope Wilton) becomes the closest to a villain in the first film, shown to be frozen by concern about food safety, cruel to children on the street in response to their persistent attention, and uninterested in the history, culture, and people of India. Overwhelmed by “the climate, the squalor, the poverty” – “this country’s driving me mad,” she explains – she holes herself up in the hotel, before fleeing the country at her first opportunity (the film makes her especially worthy of the audience’s disdain to excuse the budding affair between her husband, Douglas, and Evelyn).

Even as the films critique those characters who are unable to adapt to life in India, their narrative centers are firmly English, repeatedly turning to the difference between India and its people, who often serve as mere devices to forward the development of the white characters into ideal active agers. As reviewer Mahajan pointed out, when Evelyn teaches a group of “fawning call-center workers how to speak politely to British customers,” or Muriel is the first person to treat an untouchable sweeper woman humanely, “the film relies on scenarios where foreigners get to civilize the willing natives in return for a little emotional catharsis.” In the second film, some secondary Indian characters are affirmatively othered as classically orientalist “noble savages” and “magical negroes,”<sup>3</sup> offering the British characters special insight into their personal dilemmas. The representation of Evelyn’s uplift of her new business partner Hari (Shubhrajyoti Barat) is merited by his almost prescient plan to use ageism to negotiate a price with a textile producer and his simple intervention into Evelyn’s dawdling at beginning a romance with Douglas. Gold-digger Madge’s relationship with her driver (Rajesh Tailang) is straight out of a colonial melodrama; he is her quiet but faithful guide through both the streets of Jaipur and her romantic life, deferentially calling her “my lady” as he chauffeurs her in his vintage Ambassador. His pithy aphorisms, delivered with the understated charm of a modern guru – “there is no present like the time” – win Madge’s heart, although the film feels no need to suggest he was after it or that he would do anything other than accept her advances. Wordlessly, Madge’s smile barely intimates that she wants to sleep with him, and he, knowing as he is, needs no further cue.

The otherness of India – its risks and challenges – make it a foreign place of possibility for the British characters’ plots and personal growth. The postcolonial threat of a speeding motorbike on the dark web of streets of old Jaipur drives Douglas and Evelyn into their first physical embrace, facilitating new amorous life in old age. Fear of having accidentally hired a hit on his girlfriend from an eager Tuk-Tuk driver propels Norman’s plot through the second film,

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**3** | These films thus continue a long tradition in Western culture of characters of color in stereotypical, supporting roles, defined as idealized others and portrayed as having innate goodness, mystical insight or power put to the service of the white protagonists.

lubricating even polyamorous life in old age. The successful adaptation of the protagonists to their postcolonial setting, their emotional vivaciousness (not to mention virility), and youthful risk taking is confirmed by having the second film conclude with each of the main characters riding through the Jaipur streets on Indian motorbikes, successfully paired off romantically, just like the young Indian couple of Sonny and Sunaina.

The Best Exotic Marigold Hotel for the Elderly and Beautiful itself is the physical embodiment of Indian otherness that sets off the older characters' assertion of active aging and personal qualities generally celebrated among younger populations. A decaying building, unkempt rooms, pest infestations, barely functioning utilities, as well as the hotel's ongoing construction – these all construct a setting of risk rather than safety and sterility, the typically touted attributes of care homes. The films mock such organizing logics of care homes: the English independent living community that Douglas and Jean consider at the beginning of the first film is represented as grim and lifeless and marketed by a patronizing salesman focused on the features that attempt to keep them safe as their bodies progressively age. The irony of that “beige bloody bungalow with a sodding panic button in the ... sodding corner” is that it is only helpful if you happen to fall in that one location, Jean points out, a critique of care homes' promotion of safety in an age of intrinsic risk. The hotel, in contrast, is full of challenges and risks: an unregulated space of slippery outdoor showers (Norman falls in one without injury), multiple stairways to balconies without handrails, and a kitchen that serves up Indian dishes that overwhelm British palates and digestive systems. The staffing by non-professionals, embodied by Sonny, who is not only unprepared for his residents but also comically lacking in a basic understanding of old age, results in frequent ridiculous intergenerational behavior that not only provides moments in which ageism can be laughed at but also necessitates self-reliance on the part of the residents. India's difference becomes the proving ground of the sameness of the older characters.

## ENTREPRENEURIAL AGING

The residents of the Best Exotic Marigold Hotel prove themselves not only culturally adaptive and not risk-averse but also self-starting and entrepreneurial in their new postcolonial context. By the second film, all of the English residents are gainfully employed in India. In fact, the move to the Indian care home seems to launch them into new careers and enterprises rather than enable rest and retirement. Douglas is a tour guide, creatively overcoming his memory loss through technology and a young Indian assistant who reads the script into his earpiece. Norman and Madge manage the bar at the Viceroy social club, hustling to keep it economically viable by watering down the wine.

Presumably having left her call-center consulting gig, Evelyn has leveraged her hobby of shopping for textiles into a position as a buyer for an import company. And Muriel now manages the hotel with Sonny, serving not just as a figure of sensible steadfastness to Sonny's flights of fancy but also as the blunt, plucky spokesperson for the hotel's expansion that ultimately sells the plan to a US corporate investor.

This focus on work and enterprise demonstrates these characters' worth and merit through their performance of sameness with the middle aged who are defined by their work lives, and negates potential difference as non-productive elderly (van Dyk, "Othering" 2). Through their flexibility, mobility, creativity, resourcefulness, and the construction of "entrepreneurial selves," these characters prove themselves worthy subjects of neoliberal capitalism (van Dyk, "Othering" 3; Bröckling; Ouellette and Hay) and thus perhaps no longer necessary objects of governmental support and social-welfare systems. Contemporary popular culture and political discourse associate such qualities with youth, who are seen as drivers of the new economy, whereas the elderly are celebrated, in comparison and often patronizingly, for their wisdom, experience, courtesy, and loyalty, attributes deemed less attractive by neoliberal societies (van Dyk, "Othering" 3). *BEMH* redeems the difference of its aged characters by asserting their value similar to those most celebrated by the new economy.

This assertion was made explicit in the *2ndBEMH*'s partnership with the organization Senior Entrepreneurship Works. The film's production company co-sponsored a series of summits on "Senior & Multi-Generational Entrepreneurship" in a dozen world cities in 2015, which, in addition to discussions on ways to "pivot corporate and government cultures, policies and legislation to embrace and leverage the valuable expertise of the Experienced Economy (50+ workers) in new business startups and multi-generational workforces," included pre-release screenings of the new film. The film's closing credits end with the statement, "At any age, life can be an adventure," directing viewers to a website with information on the film's "alliance" with Senior Entrepreneurship Works. In a direct statement of the link between the positive promotion of old age and capitalist economics, the organization states on the site: "Changing the negative paradigm of aging and amplifying the economic vitality of people 50 and older is not just a social issue; it's an unprecedented global economic opportunity," shifting old people "from burden to benefit," as the organization's home page continues (Participant Media; Global Institute for Experienced Entrepreneurship). Old people are marketed to corporations and governments through their positively valenced difference – their experience, their wisdom, and their assumed dormant productivity in retirement – as well as the assertion of their similarity to younger generations, by "unleashing the potential" of entrepreneurship with experience in the Third Age, a combination the group

awkwardly calls “experieneurship.” Such organizations mobilize the assumption of a demographic and economic crisis of a large aging population without guarantees of social-welfare commitments by the state or corporations. Rather than fighting for such support, they offer such neoliberal market solutions as empowering individualized risk taking and flexibilized self-exploitation in the discourse of active aging, framing their work as “creating systems to boost economic self-reliance, vitality and growth.”

The representation of *BEMH*’s characters as the prototype of the neoliberal free-agent aged romanticizes a global aging empowered by free flows of people across national borders, enterprisingly creating wealth for themselves in the service and cultural industries characteristic of the new economy. But India, like most Global South *and* Global North countries, has an immigration policy and visa process that restrict non-citizens’ employment. In reality, cross-border employment is complicated by national regulations and oversight, and is not one characterized by older people falling into or experimenting with new professions. *BEMH*’s retiree migrant characters may be working in informal arrangements, paid “under the table” without any official certification, parlaying their English-language skills and expatriate cultural capital into service and retail work for foreign consumers in the era of a globalized, free-market India. The films emphasize the romantic dimensions of embarking on these endeavors but pay little attention to the precarity of the work: the lack of job security, poor and irregular pay, lack of benefits, and in many cases the illegality of these jobs for the types of visas these characters would actually be eligible for.

The precarity of the employment with which retirement migrants finance their aging abroad, as well as their creativity in the face of economic pressures, is evidenced by the wealth of online writing about old-age migration itself. Much of it is produced by older people who moved abroad for their retirement and now fund themselves through freelance employment, advising others on how to “Retire Better – For Less – Overseas,” “Retire in Comfort with Panama’s *Pensionado* Visa” or “Fund Your New Life Overseas With These 6 Portable Careers” in subscription newsletters and magazines promoting retirement abroad such as *International Living*. (Not surprisingly, advertising-supported blogging about the locale, photography of local sites, English-language instruction, opening a tourist B&B, and import-export endeavors are some of the proposed “portable careers.”) These old-age migrants supplement their own retirement finances with income generated from being local experts as anchor retirees in informal and often precarious cultural work that bolsters the transnational retirement industry itself.

## THE DEVELOPMENT OF OLD AGE

While in *BEMH* the residents are celebrated for their employment and productivity, in the development policies and discourses of Global South countries trying to attract old-age migrants they are valued instead for their consumptive power. At the time of the 2011 filming of *BEMH*, there were no Indian care homes catering specifically to foreign nationals, as anthropologist of Indian care homes Sarah Lamb notes (192), but the business model of “outsourcing old age,” as Sonny proclaims it, is not merely speculative fiction, as many countries had already established policies to attract old-age migrants to profit from the movement of older Global Northerners and their capital. Attracting senior migrants by constructing “transnational corporate care markets” has become a development strategy for several countries, although there has been scant scholarly attention paid to it (Yeates, “Going Global” 1116; Toyota and Xiang). Older migrants who can demonstrate stable incomes, savings accounts with local banks, investment in real estate, or portable health insurance are seen as sources of foreign reserves of dollars, pounds, and Euros and as consumers who will stimulate economies with their purchasing and employment of local medical, service, and eventually care providers. A nexus of state and industrial forces work to target “quality” old-age migrants, as an official with Thailand’s Long-Stay Tourism Management agency described those expected “to become sustained high-power consumers in residence” (Toyota and Xiang 714).

A number of states around the world have established policies to attract retirees, encouraged by real estate, health care, and other service industries hoping to profit from a potential “retirement tsunami” of old age migrants on their shores, as the Philippine Retirement Authority celebrated it (Toyota and Xiang 712), evocatively and ironically with reference to a destructive natural disaster. In the Global North the term has frequently been deployed in phrases such as “gray tsunami” and “silver tsunami” as a negative, alarmist metaphor for an impending demographic “crisis” of aging populations (Charise 1–2). But for Global South countries hoping to profit from old-age migration, the tsunami is remade as a powerful resource, co-constructed by Northern societal perceptions and priorities. These countries have promoted themselves as old-age havens for prospective waves of foreign nationals, billing themselves as warm locales offering a low cost of living, long-term residency, retiree discounts, and even tax protections. The Philippines, Malaysia, Thailand, Panama, Ecuador, and Belize are exemplary, offering programs that compete with each other to attract people of a certain age and income with benefits such as multiple-entry visas to allow for long-term residency, tax-free pensions and annuities remitted to the country, exemptions from customs duties on the importation of personal effects and from taxes on the purchase of some goods, and generous discounts on services like utility bills, public transportation, airline tickets, hospital

bills, and closing costs for home loans. Panama, for example, combines a visa program with generous benefits and discounts on services to retirees, low tax rates, and incentives for real-estate investment, establishing what *International Living* named “the world’s best retirement incentive program.” It has become one of the fastest-growing destinations for international retirees, “reaching what one called a ‘frenzy’ in Panama” (“Panama Visa and Residency Information”; Dixon et al. 1). Similarly, the Philippines, whose nursing schools served as metaphorical “export processing zones,” producing large numbers of nurses and care workers who labor in care industries around the world, undertook a strategy of encouraging the retirement industry in the country to put that care labor to work locally. The Philippine Retirement Authority (PRA), together with the business association Philippine Retirement Inc., lobbied the government for favorable policies toward the retirement industry, including the recognition of retirement developments as literal Special Economic Zones, entitling them to income-tax deduction from 5 to 35 per cent (Toyota and Xiang 714; Philippine Retirement Authority). By early 2016, 42,511 foreigners were enrolled in the Philippine retirement plan, and the PRA aims to more than double that number to 100,000 by 2020 (N. Morales). The PRA estimated that the retirement industry, which it identifies as “housing, healthcare and lifestyle” businesses, yielded revenue of US\$ 2.4 billion in 2011 and was then expected to have doubled by 2016 (Toyota and Xiang 710).

The decision to relocate in old age may be motivated by economic considerations, but the determination of location takes into account practical concerns of health care, safety, and quality and availability of services, as well as considerations of climate, geographic and cultural proximity and familiarity (often derived from histories of colonial and neocolonial power), language, foreign investment, even official foreign currencies, producing certain locales as appealingly foreign but familiar to old-age migrants (Dixon et al.; Warnes and Patterson). Many of the destinations for old-age migrants do not have a history of care homes, as older people have traditionally lived with younger family members or brought in domestic workers to provide assistance and care in their own homes. But multiple transnational economic, social, and cultural forces are driving demand. Younger generations have migrated to other national and international locales, some to work in care industries themselves, setting off a “global care chain” for dependent children and parents who have remained at home (Hochschild; Parreñas, *Servants and Force*; Yeates, *Globalising*). Their absence as caregivers is filled through the financial support they provide for parents to live in care homes. The concept and business model of the care home has also globalized, as Lamb argues, with owners modifying and adapting the form to appeal to different cultural and social settings, such that it is not simply a Western transplant but takes root in an altered form depending on local understanding of aging, care, and dependence. At the same time, Global North



old-age migrants moving to warmer, more affordable locations are aging in these new places and looking to move into care homes that fit their conception of aging but now in a foreign place.

Most of those moving abroad for retirement could be called “young-old,” those who are deemed the most desirable age demographic by these old-age migration programs. The Philippine Retirement Authority’s General Manager Valentino Cabansag has described the agency’s strategy: “Right now, it’s the ambulatory and fun-loving retirees that we are targeting” (N. Morales). But with the large numbers of young-old expatriates living in these locales, even if a large number of them return to their home countries, there will be significant demand for care homes for the remaining foreign seniors, which hospital and care-home developers are beginning to meet in some locations. In Mexico, for example, Roberto Ibarra’s 2011 study noted that there were roughly 40,000 to 80,000 North American retirees in just the central Mexican communities of Lake Chapala and San Miguel de Allende, resulting in “growing demand for assisted-living facilities” in Mexico, especially around expatriate communities (“Health Care in Mexico”). Care homes in Mexico cost half of what one would pay in the United States, with a range of amenities, including 24/7 nursing care, serviced by a more affordable workforce. Abbeyfield, an independent living facility in the Lake Chapala area, offers one-bedroom *casitas* beside lap-pools and lush gardens for a little more than \$1,000 a month, including three home-cooked meals a day, all utilities including TV and internet, and on-call 24-hour emergency assistance; in contrast, independent living in the United States costs an average of \$2,500 a month (McCleery). Assisted-living and nursing homes in Lake Chapala, like Lakeside Care, cost between \$1,400 and \$2,000 a month for full spectrum care (the only additional costs to the resident are for medicine and doctor visits); in the United States, such a care home would be \$3,800 a month for assisted living to upwards of \$7,000 at a nursing home. In 2016 there are at least nine care homes in the Lake Chapala area, two in San Miguel de Allende, and two in Puerto Vallarta catering to English-speaking residents (Carrel). The English-language website of the Mexican Association of Retirement Assistance (AMAR), which promotes the development of the Mexican retirement migration industry and lobbies government for investment in and rationalization of the sector, includes advertisements for a dozen more care homes, ranging from independent living to Alzheimer’s/dementia care facilities. Few data are available on how many foreign nationals live in care homes in Mexico, but it is clear that the private health-care industry plans to expand its reach to North Americans, building on growing medical tourism to develop more assisted-living facilities, care homes, and in-home nursing-care programs (Ibarra 98).

Clearly, outsourcing old age is an economic strategy considered by both people and states, the latter not just in the Global South but also in the Global

North, as intimated by Muriel's experience in *BEMH*. From the early 1990s there have been sustained calls to extend Medicare (the US national health insurance program for people over 65, as well as for younger people with disability status) to recipients residing outside the country. American retirees abroad have been backed by lobbying from corporate interests – including Mexican real estate developers and the private health-care industry dominated by large, US-based corporations – who see the migration of Medicare-eligible populations as “a globalization process that transforms Medicare trust funds, and indeed health, into mobile transnational capital,” encouraging the privatization and profitability of health-care systems abroad (Ibarra 104). In the United States, the proposal has been pitched to politicians as a strategy to cut costs for taxpayers, potentially reducing Medicare spending by 35 to 70 per cent by paying for cheaper medical services in locations like Mexico (Ibarra 97).

In this emerging transnational care market, Global South care homes project themselves as alternatives responding to discontent with care homes in the North (Horn et al. 169, 172). Whereas care homes in the developed world are understood as relatively safe, sanitary, managed and regulated, they are also perceived as rule-bound, impersonal, routinized, and understaffed institutions (Baines and Daly; Banerjee and Armstrong; Daly et al.; Lopez; Commission on Dignity in Care). In contrast, there is little government regulation or quality oversight over care homes in most Global South locations, but they represent themselves as having a comparative care advantage attributed to economic and cultural conditions producing more affordable, plentiful, and intrinsically caring staff who offer more individualized and affectionate attention to residents, even if that care is less trained, professional, and accountable. Marketing materials and press reporting often suggest that care and respect for the elderly are culturally essential – even natural – to populations in the Global South, offering oversimplified explanations of the prevalence of multigenerational households and relying heavily on stereotypes of eager and accommodating women of color as caregivers. Horn et al. quote the website of a Thai care home catering to German residents: “Frail, elderly people are held in high regard in Thai society and deserve respect and good affectionate care ... As a result, people in Thailand are highly motivated to care for elderly people ... One outstanding quality of the care provided by the Thai staff is the warm-hearted, tender way they deal with elderly, dependent people: they are physically close and respectful” (170). As Lamb points out, the assumption that “Asians” are more natural caregivers or have a culture of looking after the elderly is belied by the fact that most of the foreign residents in Thai, Philippine, and Malaysian care homes are Asian themselves, but from wealthier countries. Similar portrayals of Latin American caregivers and care homes abound. As the owner of Mexican Lakeside Care insists, “they have great respect for the elderly and they will go out of their way to help an elderly person,” with a resident affirming, “people

here have compassion written into their DNA, they do it before they know it. The caring is just like being in an extended family" (McCleery). This emphasis on individualized care and essentialized cultural character over professionalization, regulation or oversight results in practices and popular representations of care relationships as intimate (more hands-on), familial (framed as treating people as members of their family), and informal (less skilled and routinized), with both positive and negative repercussions for caregivers and care receivers alike (Horn et al.). And, importantly, these attributes are framed in comparison with Global North care systems in a globalized care market, as one expat writing from Mexico affirms: "The warmth and level of genuine caring is surprising to many foreigners who are accustomed to perfunctory treatment dispensed within institutional settings" (Paxson).

Muriel and Anokhi's (Seema Azmi) relationship in *BEMH* characterizes this logic. Anokhi's care, dutiful and deferential in the face of Muriel's disregard and even hostility as she recuperates from hip surgery, is inscrutable in orientalist fashion. The audience is forced to assume that she is an intrinsic caregiver, while the film offers the reasoning that she is culturally naturalized to service due to her lot in life as a Dalit, or "untouchable," in the Indian caste system. Anokhi invites Muriel to her family's home, because she is "the only one that acknowledges her," regardless of evidence in the previous scenes to the contrary. In the second film Anokhi plays little role in the plot; she has already performed her larger narrative service of helping Muriel to become less racist and is now relegated back to being virtually invisible, if not literally untouchable. But she is there, dotingly, in the film's last scene as Muriel faces perhaps the final moments of her life, representing the closest thing she has to family. The *BEMH* films thus conclude their work of constructing a Third Age defined by neoliberal mobility, adaptability, resourcefulness, and risk taking through an encounter with the challenges and difference of the Third World. For when these characters inevitably progress to the Fourth Age, these films tell us, they will have people essentially qualified by their challenges and difference to care for them at the end of life.

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# Who Cares?

## The Terror of Dementia in Ian McEwan's *Saturday*

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*Peter Simonsen*

Why aren't they screaming?

PHILIP LARKIN, "THE OLD FOOLS" (131)

I fear being the elderly friend, a man of both refinement and squeamishness, whose eyes showed animal panic when the nurse in the residential home announced in front of visitors that it was time to change his nappy. I fear the nervous laugh I shall give when I don't quite get an allusion or have forgotten a shared memory, or a familiar face, and then begin to mistrust much of what I think I know, and finally mistrust all of it. I fear the catheter and the stairlift, the oozing body and the wasting brain.

JULIAN BARNES, *NOTHING TO BE FRIGHTENED OF* (140–41)

Ian McEwan's *Saturday* (2005) is typically read as a novel about the everyday fears and constant worries that entered many people's lives in the aftermath of the terrorist attacks of 11 September 2001. The burning plane that opens the novel causes protagonist Henry Perowne to think of terrorism and to embody the pervasive sense of insecurity in the post-9/11 era. This is captured in his sense that "Now we breathe a different air" (32) and is emphasized throughout the novel, where we follow the ever-present news reporting both from the big anti-war demonstration that takes place on the day the novel is set, Saturday 15 February 2003, and from the story of the burning plane. This story turns out to have nothing to do with terror, but it still manages to accomplish the goal of modern terrorism: to spread feelings of fear, insecurity, and precariousness through a perceived sense of risk of seemingly arbitrary acts of aggression (Butler). In the novel, the big, abstract fear of terrorism is concretized when Perowne and his family become the victims of another kind of terrorism – domestic terror – when a thug, Baxter, with whom Perowne was involved in a

seemingly innocent car accident earlier in the day, forces his way into Perowne's otherwise safe house and holds his family hostage, threatening to rape his daughter, Daisy, who is pregnant.

This critical emphasis on violent terrorism, which indeed calls our attention to what takes up most narrative space in the novel, however, has obfuscated an equally important aspect of this rich and multifaceted work: the way in which it captures the growing fears and constant worries of many people about ending up in a nursing home as a dementia patient. Fear of dementia, most often a fear of the most common disease to cause dementia, Alzheimer's disease, is the fear of ending up as "living dead" behind closed doors at the mercy of casual caregivers. As Megan-Jane Johnstone notes in her study of media representations of Alzheimer's disease, it

has been controversially portrayed as "the disease of the century" that is poised to have a near catastrophic impact on the world's healthcare systems as its population ages. This representation has given rise to a profound terror of the disease and a range of individual and societal risks believed to be associated with it. This terror and related anxieties have been positioned as requiring a remedy. (xvii)

As Johnstone continues, the remedy for this kind of "terror" is often and increasingly – and problematically, from both moral and basic humanistic perspectives – "pre-emptive and beneficent euthanasia" (xvii). Among the many problems involved with this growing public discourse in favour of euthanasia is the culturally constructed image it promotes of the Alzheimer's patient as a non-human "other," as just a vegetable being or empty shell, when in fact there is increasing awareness among dementia researchers and carers that dementia patients live lives worth protecting and worth caring about and for (Kitwood; Leibling and Cohn; Hughes).

The risks of terrorism and dementia are curiously paralleled in *Saturday*. The novel offers, through an unobtrusive third-person narrator focalized entirely through Henry's intensely self-conscious and self-reflective mind, a finely detailed and psychologically realistic and engaging investigation of popular feelings about these contemporary life risks and the ways in which people try to deal with them: by containing one risk within a nursing facility with all the semblance of a private home; by trying to exclude the other by turning private homes almost into fortresses. In both instances, the novel suggests, such safety measures don't add up and people are intruded upon and made to feel unsafe and to vicariously experience victimhood: a terrorist forces his way into a private home and threatens a family; and in an eerily parallel manner, Henry feels obliged to visit his mother, Lily, who has Alzheimer's disease, in her nursing home, which makes him feel like a potential Alzheimer's victim himself. Both home visits/intrusions cause fear and anxiety and give those

involved – and the reader – a sense of the precariousness of contemporary life even as the novel, by portraying only Henry's mind, also offers glimpses into and allows readers to imagine what life might feel like both for the terrorist and for the dementia patient, who readers are made to realize represent much more than their feared pathologies.

## THE NURSING HOME IN THE CONTEMPORARY CULTURAL IMAGINARY

The house of fiction has many shapes and rooms. Houses and homes carry much metaphorical weight in fiction as symbolic of the state of mind of their inhabitants, and as physical, material “sites” (Alworth) they also function to shape and mould characters and plots. As geographer Yi-Fu Tuan points out in *Space and Place*, “The built environment, like language, has the power to define and refine sensibility. It can sharpen and enlarge consciousness” (107). A growing number of Western literary fictions take place in and around nursing-home facilities, with the “home” playing a significant role in plot and character development as a shaper of consciousness. According to Tuan, “Unique to human beings as primates is the sense of the home as a place where the sick and the injured can recover under solicitous care” (137). In other words, to reflect on nursing homes and other spaces of assisted living is in a profound sense to reflect on what it means to be human and on what localities most deeply shape our sensibilities and consciousness as humans.

Authors and readers are attracted to this, for many, off-putting, both intimate and claustrophobic setting for a number of other reasons as well, of course. Among them, surely, is the basic fact that our societies are aging, and more and more such nursing facilities are needed to take care of a growing number of very old, frail, and dependent individuals, whose families have increasingly left behind traditional nuclear family structures where the generations lived together and the women typically stayed at home and took care of the children and the elderly. These demographic and family-related changes are again complexly connected to the accelerating individualization and consumer culture of free choice in the West, where we place great emphasis on self-realization and less emphasis on being attached to groups founded in solidarity and self-sacrifice. This goes a long way toward explaining the prevalent emotional coding of the nursing home in this fiction as a place of fear and terror, where people fear not just the death that concludes any nursing-home stay (you don't move out once you've moved in) but also the increasing loss of personal autonomy and dependency on the care of others on whom many lives come to depend. Feelings of fear are eloquently articulated by Philip Larkin and Julian Barnes in my epigraphs and are reproduced by historian of the nursing home Megan Davies, as quoted by literary gerontologist Sara Jamieson in her

argument against such traditional understandings of the nursing home, when she argues that even though many nursing homes “may aspire to provide a ‘warm, home-like ambience,’ this inevitably conflicts with the reality of how life in residential care is shaped by ‘rules and routine imposed from above’” (8). Combined with these feelings is a prevalent ugly sense of bad conscience and guilt on behalf of the relatives, partners, or adult children, who put their loved ones into nursing homes in order to live their own lives.

This fear of loss of control and self-determination in combination with guilt at not caring enough by one’s own or others’ judgement fuels many nursing-home narratives, whose vision is often based on somewhat old-fashioned notions of such institutions, derived from Victorian poor houses, as quasi-prison facilities and has led writers to imagine various alternatives. A number of such fictions have reached large audiences both as novels and through film adaptations. Deborah Moggach’s *These Foolish Things* (adapted as *The Best Exotic Marigold Hotel* and its sequel) and Jonas Jonasson’s *The Hundred-Year-Old Man Who Climbed Out of the Window and Disappeared* (also adapted as a film) are both about handling the fear of the nursing home through escaping the traditional institution. In Moggach, a key character, the aged widow Norman, keeps getting thrown out of standard nursing homes because he is filthy and a pervert, so he has to stay with his adult daughter, Pauline, and her Indian husband, Ravi Kapoor. Norman terrorizes the household and jeopardizes the marriage, so Ravi and a cousin come up with a plan: outsource British elder care to India, build nursing homes in the former colony where there is cheap labour, and move the elderly out of sight to enable their relatives to go on with their lives as they choose.

The actual nursing home in *These Foolish Things* is hardly a nursing home per se but rather a kind of run-down Indian all-inclusive holiday resort where resourceful British old-age pensioners in the “Third Age” move for a number of reasons – none of them being because they can’t take care of themselves any longer (note the film title’s use of “hotel” as euphemism for nursing home). In Jonasson’s phenomenally popular “geezer lit” novel, the centenarian protagonist Allan Karlsson escapes from a traditional nursing home and its regime, which is embodied in the Director, whose strict rules and regulations regarding hours, liquor intake, and smoking Allan will not submit to. Instead, he takes off on a fantastic trip around Sweden with a suitcase full of money, with criminals and police on his trail and a luxurious ending ahead of him, where he realizes that he was not, as he had thought, neutered and impotent but can in fact have sex with a Balinese beauty. Jonasson’s nursing home does not take up much narrative space but is a crucial engine for the plot and action as well as a telling sounding board that reveals the character of the protagonist as someone preferably on the move. Yet it reads almost like a parody of an old-fashioned panoptic “total institution” (Goffman), where the will and freedom of the

inhabitants are controlled and they experience degrading dehumanization as they are forced to develop docile, obedient, and fearful “institutional selves” (Gubrium and Holstein). The main character is a cartoon-like figure for the new, active, mobile, and empowered generations of elderly individuals who take matters into their own hands and aspire to deny the biology of aging through continuous activity. A common aspect of these two novels is that their main characters are not demented and do not really need the nursing home with its offer of care and protection.

This is not to say that all nursing-home fictions seem to misrepresent the realities of the nursing home, either through rendering them exotic, as in Moggach, or through painting a too stereotypically bleak and in many senses outdated picture of the nursing home, as in Jonasson. A number of contemporary Danish novels, for instance, depart from the otherwise dominant norm in Danish fiction set in nursing homes that the place is dehumanizing and informed by a reign of terror that denies individuality. Instead, some novels and short fictions provide more nuanced and sometimes even hopeful representations of the care work carried out in and by these institutions, which enable new forms of living for both the elderly and their adult children (Simonsen). As Sara Jamieson and Patricia Life have more recently argued in almost parallel readings of Alice Munro and other Canadian fictions, the nursing home in “The Bear Came over the Mountain” also abandons the stereotypical Victorian nursing-home/poor-house model and may provide much needed “shelter” from the outside world. Documenting a tendency in recent Canadian fictions toward “a more positive public perception of late-life housing” (243) where characters nonetheless must still resist the otherwise oppressive regime of the institution, Life even suggests that “some forgetting” (255) associated with dementia may be experienced as positive, to the extent that what is forgotten may be related to traumatic experiences in the past, such as a husband’s adultery. The nursing home can be, and is increasingly being, imagined as a place for living and loving, to some extent, on one’s own conditions; a place where, as Life puts it, characters “can find a safe haven and shake off the shackles of their former lives” (244) even as they may experience various forms of dementia. Surely we need such images and narratives (what Life calls “aging-as-opportunity narratives,” 256) as our culture and societies age and our reality is transformed in this image.

## McEwan’s *Saturday* as Nursing-Home Narrative

McEwan’s *Saturday* can be read as a nursing-home narrative, the genre that “presents fictional texts and films that are either set in nursing homes or deal with the complex array of problems and feelings associated with moving oneself

or relatives into a caregiving institution” (Kribernegg 190). Midway through the novel, Henry arrives at his mother’s nursing home:

By the standards of old people’s homes, Suffolk Place is minute – three houses have been knocked through to make one, and an annexe has been added. Out front, privet hedges still mark the old garden boundaries and two laburnum trees survive. One of the three front gardens has been cemented over to make parking space for two cars. Two oversized dustbins behind a lattice fence are the only institutional clues. (158)

Far from a big, dehumanizing institution, this nursing home exudes homeliness and familiarity, though the focus on waste and the fence set the tone for the scene. While the visit takes up little narrative space in the novel, this space importantly constitutes the dead centre of the text and features its protagonist away from his comfort zone and with his guard down. The visit, in fact, is crucial to understanding the novel in the sense that the nursing home at its heart possesses an eerie kind of agency with respect to the main plot and characterization. Far more than a mere background, the setting alerts readers to what the novel is ultimately and most centrally about: Henry Perowne’s own fear of death, change, and mutability, and his intense need, but ultimate failure, to be in full control as a self-determined, autonomous Cartesian Subject.

Titled from the day on which its action unfolds – Saturday 15 February 2003, which saw hundreds of thousands march against the allied intervention in Iraq – the novel provides a trenchant commentary on global politics in the twenty-first century while also alluding to such modernist forerunners as Joyce’s *Ulysses* and Woolf’s *Mrs Dalloway*, which also follow their protagonists during one day’s movements through a city. It also, centrally, flags the subject matter of time and the experience of being in time. Indeed, at the end of the novel and a hectic day on which a complex plot has been resolved in a very dramatic climax, an exhausted protagonist Henry reflects:

He feels himself turning on a giant wheel, like the Eye on the south bank of the Thames, just about to arrive at the highest point – he’s poised on a hinge of perception, before the drop, and can see ahead calmly. Or it’s the eastward turn of the earth he imagines, delivering him towards the dawn at a stately thousand miles an hour. If he counts on sleep rather than the clock to divide the days, then this is still his Saturday, dropping far below him, as deep as a lifetime. And from here, from the top of his day, he can see far ahead, before the descent begins. Sunday doesn’t ring with the same promise and vigour as the day before. (272–73)

McEwan here alludes to the traditional iconographic representation of the “stages of man’s life” in terms of a wheel as he masterfully uses both the London Eye and the spinning of the earth as micro-macro images (similarly

to the way in which he deals with two kinds of terror) to capture the sense of time passing and life moving toward the end, which is what is on Henry's mind more than anything. He is indeed on top of everything: he has a great job as neurosurgeon, a perfect marriage to a successful woman, Rosalind, with whom he has great sex and two successful children (one a poet, Daisy, the other, Theo, a musician), a big townhouse in the heart of Bloomsbury, and a Mercedes. What more could he desire? Despite all this – or rather because of all that he has – he fears the death and decline that he cannot control (“Sunday doesn’t ring with the same promise and vigour as the day before” [273]). And, because he is a control freak, this bothers him more than anything.

A telling instance of Henry's need to feel protected occurs on his way to visit his mother when he sits in his car, exhausted, and takes a nap: “Without looking, he finds the button that secures the car. The door locks are activated in rapid sequence, little resonating clunks, four semiquavers that lull him further. An ancient evolutionary dilemma: the need to sleep, the fear of being eaten. Resolved at last, by central locking” (121). Readers may sense a mocking implicit author setting Henry up for trouble for seeking this intense kind of protection, and indeed this passage refers back to a similar one involving locks earlier in the novel. Henry's townhouse, like his Mercedes, physically embodies and illustrates his need for control, shelter, and protection from the outside world. The outside is dangerous and hard to understand and intrudes upon him as he awakens during the night, opens a window, sees a plane on fire on its way to Heathrow, and instantly thinks terrorism. Having woken up, Henry goes to the kitchen and has a chat with his son, and on his way back to bed he notes the house's doors. Interspersed with the description of the doors is a muted mental note on aging as decline and physical space as a means of protection:

He feels feeble in his knees, in the quadriceps, as he goes up the stairs, making use of the handrail. This is how it will be in his seventies. He crosses the hallway, soothed by the cool touch of the smooth stone flags under his bare feet. On his way to the main stairs, he pauses by the double front doors. They give straight on to the street that leads into the square, and in his exhaustion they suddenly loom before him strangely with their accretions – three stout Banham locks, two black iron bolts as old as the house, two tempered steel security chains, a spyhole with a brass cover, the box of electronics that works the Entryphone system, the red panic button, the alarm pad with its softly gleaming digits. Such defences, such mundane embattlement: beware of the city's poor, the drug-addicted, the downright bad. (36–37)

As the novel progresses toward its climax, we see this elaborate defensive system being broken as home intruders force Henry's wife to let them in and to recognize that it is not possible to protect oneself from “the downright bad.” Yet it is Perowne's thoughts of growing old and frail (“This is how it will be

in his seventies”) that frame this elaborate, almost heavy-handed description of the physical defence system. Henry seeks protection not just from outside intruders; he also dreams of protecting himself from the biological process of aging even as he knows – as a medical doctor and brain surgeon – that there is no way of keeping the body safe from those cellular processes of decline.

This is most clear in Henry’s visit to his mother, who lives in a nursing home close to his childhood home. This visit leads to his feelings of fear of death in the novel’s central chapter. Henry aspires to a state of thoughtlessness that his Saturdays are meant to represent, yet this Saturday is different. Waking up, he saw the airplane on fire and immediately thought of terrorism and the attacks on the Twin Towers just eighteen months earlier. In addition to this reminder of his vulnerability, Henry has been involved in a minor car accident and barely escaped being beaten up. He made it away only because he used his skills as doctor to diagnose the thug, Baxter, with Huntington’s Disease and lied about possible new treatment methods, something that deflated a pent-up situation and allowed him to escape. Yet the fear of Baxter, along with the worries about the new world order, war, and terror, inform his otherwise tranquil Saturday. Driving away from a lost game of squash to visit his mother, he reflects on the “gently tilting negative pitch of his mood”:

Saturdays he’s accustomed to being thoughtlessly content, and here he is for the second time this morning sifting the elements of a darker mood. What’s giving him the shivers? Not the lost game, or the scrape with Baxter, or even the broken night [when he awoke to see the plane on fire], though they all must have some effect. Perhaps it’s merely the prospect of the afternoon when he’ll head out towards the immensity of suburbs around Perivale. While there was a squash game posed between himself and this visit, he felt protected. Now there’s only the purchase of fish. His mother no longer possesses the faculties to anticipate his arrival, recognize him when he’s with her, or remember him after he’s left. An empty visit. She doesn’t expect him and she wouldn’t be disappointed if he failed to show up. It’s like taking flowers to a graveside – the true business is with the past. But she can raise a cup of tea to her mouth, and though she can’t put a name to his face, or conjure any association, she’s content with him sitting there, listening to her ramble. She’s content with anyone. He hates going to see her, he despises himself if he stays away too long. (124–25)

In this crucial passage right in the middle of the novel, the ambivalent feelings of relatives toward nursing-home inhabitants are revealed as the son is torn between different emotions about his mother, and the narrator reveals how much emotional intensity is involved in his relationship with her. Laid bare in this passage are Henry’s immense selfishness and need to feel protected: the emptiness of the visit concerns him, and he seems to feel sorry for himself both when he goes to see her and when he doesn’t.



At the rhetorical level, we note that the same adjective is used to capture his sense of a perfect Saturday and the mother's feeling when someone sits with her: "content." To be content for Henry is to be "thoughtless": not to be self-aware, reflective, self-conscious. This state of being is coded positive as far as Henry is concerned, close to bliss and the state of being happy, yet McEwan subtly links that sense of thoughtlessness with his mother, whose "thoughtlessness" Henry fears more than anything (more than terrorism, losing at sports or being beaten up by Baxter). Yet Henry knows what he has and would not know he had lost it if he were in his mother's shoes. He cherishes his life too much not to be terrified when he finally sees her. Driving toward her nursing home, he "finds he's feeling better about seeing his mother":

He knows the routine well enough. Once they're established together, face to face, with their cups of dark brown tea, the tragedy of her situation will be obscured behind the banality of detail, of managing the suffocating minutes, of inattentive listening. Being with her isn't so difficult. The hard part is when he comes away, before this visit merges in memory with all the rest, when the woman she once was haunts him as he stands by the front door and leans down to kiss her goodbye. That's when he feels he's betraying her, leaving her behind in her shrunken life, sneaking away to the riches, the secret hoard of his own existence. (152-53)

It seems only natural that Henry should interpret his mother's situation as a "tragedy," given everything she has lost (which she doesn't know anymore). Yet, and despite the fact that a son will find his mother's failure to recognize him as her son hard to bear (which is what takes place during all these visits when she confuses him with an aunt), his interpretation that her situation is a "tragedy" is subtly put into doubt by the narrator.

This happens when the narrator begins to open up for a reading of the mother's state of mind and being that Henry hardly acknowledges but that McEwan's imagination dares to probe, as he suggests that maybe elderly people with dementia are indeed happy. Upon first seeing her, readers learn that it is hard to tell if she is "actually happy. Sometimes she laughs, at others she describes shadowy disputes and grievances, and her voice becomes indignant" (165). Knowing how to care for her, Henry steers her away from agitated subjects and prods her: "If she becomes too agitated by the story she's telling, Henry will cut in and laugh and say, 'Mum, that's really very funny!' Being suggestible, she'll laugh too and her mood will shift, and the story she tells him will be happier" (165). As they prepare to leave and walk together through the nursing home, they meet another inhabitant, Cyril: "He's the home's resident gent, sweet-mannered, marooned in one particular, well-defined fantasy: he believes he owns a large estate and is obliged to go around visiting his tenants and be scrupulously polite. Perowne has never seen him unhappy" (166). And

finally, as they are about to split up: "Lily is happier now, and leans her head against his arm. As they come into the hall they see Jenny Lavin by the door, already raising her hand to the high double security lock and smiling in their direction. Just then his mother pats his hand with a feathery touch and says, 'Out here it only looks like a garden, Aunty, but it's the countryside really and you can go for miles'" (167).

On the one hand, the text suggests that the elderly nursing-home inhabitants with dementia are happy, or at least capable of experiencing happiness, and that they don't inhabit a "tragedy"; the true tragedy is felt by the relatives, in this fiction at least. On the other hand, they hardly have a clear idea of who they are and where they are. Cyril inhabits a fantasy, and Lily thinks Henry is her aunt and that she is outdoors. So does it make sense to think of them as happy? Indeed, the impression we get of the nursing-home inhabitants is in an eerie sense that of a perpetual bliss of forgetfulness and a lack of self-consciousness, in contrast to Henry's (tragic?) anxiety that "in thirty-five years or less it could be him, stripped of everything he does and owns, a shriveled figure meandering in front of Theo or Daisy [his children], while they wait to leave and return to a life of which he'll have no comprehension" (165). Henry fears his mother's fate, which he sums up as "[m]ental death" (165), becoming a ghost that haunts his relatives, more than anything: "He isn't ready to die, and nor is he ready to half die" (165). So he seeks to control his life and master the risk of dementia through diet and exercise: "No cheese then. He'll be ruthless with himself in his pursuit of boundless health to avoid his mother's fate. Mental death" (165). Yet prolonging life only increases the risk, and again: if these elderly individuals are happy, why fear their condition so much?

There is nothing scary or dehumanizing about the specific nursing home, whose staff is described sympathetically as attentive and as striking a familiar mode of interaction with Henry. Arriving for his visit, Henry is met by one of the caregivers, Jenny, who opens the door as usual: "'She's waiting for you,' Jenny says. They both know this is a neurological impossibility. Even boredom is beyond his mother's reach" (159). As a matter of fact, Henry knows the facts of the disease. His mother's Alzheimer's is slowly causing her cognitive decline: "The disease proceeds by tiny unnoticed strokes in small blood vessels in the brain. Cumulatively, the infarcts cause cognitive decline by disrupting the neural nets. She unravels in little steps" (162). Indeed, Henry's unease and anxiety are linked to his superior knowledge of the disease and the brain and the fact that, despite his talent and almost godlike sense of himself as a neurosurgeon, there is nothing he can do to alter his mother's situation and almost nothing he can do to minimize his own risk of ending up in her shoes. No matter how many locks and security systems he surrounds himself with, they will not keep him safe from this condition.

The nursing-home visit can enable readers to understand the novel as contributing centrally to the cultural work of reimagining the nursing home as a place of continued living and even loving and happy forgetting. As mentioned above, *Saturday* has not yet been discussed as a nursing-home novel but rather as a post-9/11 novel. Dominic Head discusses it in connection with terrorism in his 2008 book on “the state of the novel” today, and similarly, in his 2013 study of twenty-first-century fiction, Peter Boxall considers the novel in terms of terrorism and radicalism rather than with “the disease of the century” at its heart. Most critics who focus on terror (and many who don’t) have explored how McEwan negotiates an ethics of literature responding to the threat of terror in his novel, which has many intertextual references and metafictional elements. Henry, for instance, finds that he came to understand and appreciate his mother’s intelligence only after she had lost it to dementia and from reading Jane Austen and George Eliot (prompted by his poet daughter). Reading fiction, he understood that “there was nothing small-minded about her interests” (156), which she revealed during gossip. This gossip was centrally about illnesses and operations and infidelities and the difficulties of telling good from bad people:

Jane Austen and George Eliot shared them too. Lilian Perowne wasn’t stupid or trivial, her life wasn’t unfortunate, and he had no business as a young man being condescending towards her. But it’s too late for apologies now. Unlike in Daisy’s novels, moments of precise reckonings are rare in real life ... (156)

The question is this: if Henry learned from others’ realistic fiction that his own mother was more than “just” his “small-minded” mother playing the role of the dutiful, self-sacrificing, stay-at-home housewife, that she was in fact a person with substantial inner life, thoughts, values and worth, what can we learn from reading Ian McEwan?

One perfectly timed reckoning and effective reading lesson comes when Henry’s daughter Daisy performs Matthew Arnold’s “Dover Beach” during the hostage situation, which has a transformative effect on Baxter and saves the day. Hearing the poem read out loud, believing Daisy had written it, Baxter reacts: “It’s beautiful. You know that, don’t you. It’s beautiful. And you wrote it,” and he goes on: “It makes me think about where I grew up” (222). An instance of instant bibliotherapy disarms the criminal, shows him as a person with a rich inner life, and puts him into contact with his feelings and childhood memories. This controversial episode in the novel exemplifies the potential humanizing and sensitizing good that literature might do in an otherwise hostile world (the poem is even reproduced at the end as an appendix, perhaps with the hope that the novel will make a similar difference): “Baxter fell for the magic, he was transfixed by it, and he was reminded how much he wanted to live” (278).

Yet even though the ethical dimension of this novel is the most critically examined and controversial element (see Winterhalter for an overview), no one has discussed what seems to be the limit of empathy for Henry: his own mother, into whose shoes he dare not imagine himself yet into whose shoes the text seems to suggest we should try to imagine *ourselves*, if only to accept the fact that we are at much greater risk of getting Alzheimer's disease than of being killed in terrorist attacks. So even if the novel lends itself quite easily to being read as a commentary on life in what Ulrich Beck calls "the risk society" (qtd. in Jurecic, who – extraordinarily in a book on illness narratives – neglects to consider the illness at the centre of this novel in the context of "risk narratives"), it also, and just as easily, lends itself to being read as a commentary on life in what Arthur Frank in *The Wounded Storyteller* calls "the remission society": the society where we have to learn to live with the knowledge that we are all, or will sooner or later be, in remission from one disease or another, that due to modern medicine and health systems we might be kept "well" for a long period of time, but not "cured" (8). Though we feel at risk from terrorism and sudden death (even if the statistics suggest we are not), we are also (and statistically much more so) at risk from diseases (including Alzheimer's), from which we can't be cured, but which can be treated, enabling us to live longer and longer in the remission society. Indeed, the two kinds of risk run parallel in this novel, whose main point is to familiarize its reader – through its protagonist's stream of consciousness – with those new, troubling types of risk we are facing today: terrorism and Alzheimer's disease.

Inadvertently making the reader associate Alzheimer's disease contained in a feared site, the nursing home, with contentment and happiness can be understood as this novel's way of "familiarizing" us with the risk of the disease and perhaps decreasing our fear of the nursing home. Indeed, the seemingly unselfconscious, wobbly mode of being-in-the-present the novel ascribes to Lily is so very close to the sense of being and state of mind that Henry Perowne himself cherishes, pursues, and experiences when performing open brain surgery on Baxter, whom Henry and Theo pushed down some stairs, causing him to suffer a massive head injury when the hostage situation was resolved. Henry now saves Baxter's life on the operating table even as he simultaneously consigns him to a slow and painful death from Huntington's disease. McEwan masterfully describes over several pages how the surgeon and the artist merge when he has Henry listen to Bach's Goldberg Variations while beginning the operation:

The tender, wistful Aria begins to unfold and spread, hesitantly at first, and makes the theatre seem even more spacious. At the very first stroke of sunflower yellow on pale skin, a familiar contentedness settles on Henry; it's the pleasure of knowing precisely

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what he's doing, of seeing the instruments arrayed on the trolley, of being with his firm in the muffled quiet of the theatre. (250)

We recognize the feeling of contentedness from earlier in the novel, where both Henry's usual mood on a Saturday and his mother's new state of mind are described. Now Henry re-enters that state of mind as he performs his "art of neurosurgery" (255), which he knows is limited but which, he has no doubt, will contribute to our coming to understand how the brain works. As he reflects, very little is known about "how this well-protected one kilogram or so of cells actually encodes information, how it holds experiences, memories, dreams and intentions" (254), all the stuff that make up "this bright inward cinema of thought, of sight and sound and touch bound into a vivid illusion of an instantaneous present, with a self, another brightly wrought illusion, hovering like a ghost at its centre" (254–55). At some point, Henry feels certain, we will know and maybe be able to prevent or cure diseases such as Huntington's or Alzheimer's, yet at the moment, "faced with these unknown codes, this dense and brilliant circuitry, he and his colleagues offer only brilliant plumbing" (255).

Having performed the operation successfully, Henry writes up his notes and the narrator sums up and connects Henry's state of mind to the happy elderly people's states of mind in the nursing home earlier:

For the past two hours, he's been in a dream of absorption that has dissolved all sense of time, and all awareness of the other parts of his life. Even his awareness of his own existence has vanished. He's been delivered into a pure present, free of the weight of the past or any anxieties about the future. In retrospect, though never at the time, it feels like profound happiness. It's a little like sex, in that he feels himself in another medium, but it's less obviously pleasurable, and clearly not sensual. This state of mind brings a contentment he never finds with any passive form of entertainment ... It's a feeling of clarified emptiness, of deep, muted joy. Back at work, and lovemaking and Theo's music aside, he's happier than at any other point of his day off, his valuable Saturday. There must, he concludes as he stands to leave the theatre, be something wrong with him. (258)

As I have suggested, if there is something "wrong" with Henry – and with the many readers who may identify with and envy Henry his perhaps too perfect life, family, skills, accomplishments, and possessions, as well as his smug manner of celebrating himself and what he has accomplished – it may be related to his anxieties about physical and mental decay and to his inability to feel and comprehend this as part of his life rather than as alien forces that threaten and oppose it.

## CONCLUSION

Why read nursing-home fiction? One answer is that it provides a space in which we can imagine ourselves in situations that, due to demographic changes and the aging of societies, we must increasingly become used to. These imaginings and re-imaginings of aging are necessary, on the one hand, because our elderly grow older and many into deep frailty and dependence where they do not necessarily suffer from having to move into a nursing-home facility, and, on the other hand, because if we don't consider residential care for our frail and dependent elderly, we run the risk of abandoning decades of women's work for independence from various unpaid family roles and burdens. To have one's elderly mother put into a residential home is not necessarily to signal that one does not care for her; it is in fact to make sure that someone *does* care for her, ideally under proper working conditions and not at the cost of an experienced loss of autonomy on the caregiver's side. Although he gives a good sense of the special ambience of the nursing home on a few pages, McEwan is not offering an institutional critique or evaluation. Rather, his interest is to explore what the place does to his protagonist's state of mind and to show that Henry's understanding of the nursing home may not be adequate compared to how its inhabitants experience it, given their radically other state of mind to which Henry – and Henry's reader – despite his and our skill in “mind reading” (Zunshine), do not have access but which we sense is there and in need of care.

*Saturday* can be read as a story about letting go of this fear through embracing dementia as another state of being that – at least, and this is an important caveat, at least for a short while – is in other contexts associated with the richest “moments of being.” Virginia Woolf thought of such moments of flow, where people transcend time, place, and self to experience genuine happiness. In the novel, this takes the form of what Henry thinks of as a kind of unconscious oblivion in a “biological hyperspace” (51), which informs the opening and closing scenes of the novel and frames the intense exploration of how one mind works its way through a day of extraordinary events, thoughts, and feelings. Just as Henry only learned to read his mother's mind after she got dementia by reading Jane Austen and George Eliot, who could show him what really passes through such a woman's mind, so do I suggest that we might learn to read Henry's mother's mind through reading his fearful failure to do so in this novel. And this reading lesson might make us better qualified to answer my title's question of who cares for some of our society's most precarious and vulnerable subjects.

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# Outside the Nursing-Home Narrative

## Race and Gender Exclusions in *Green Grass, Running Water*

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Patricia Life

Canada has an impressive literary tradition of works set in nursing homes. Key texts (Traill, Wilson, Laurence, Shields, Wright, Barfoot, Munro, Tostevin, Gruen, Hepburn, King) taken from the last century of Canadian English-language publishing, when considered together, illustrate patterns in age-related beliefs and behaviours in Canada and in nursing-home-narrative fiction. The texts include Gothic stories of fear of the nursing home, of aging, and of death; darkly humorous stories featuring empowered residents successfully living within care homes; and fantastical stories of escape from the home and of return to youthful behaviours and preferable habitats (see Life).

This article does not assess the texts included in this literary collection but instead considers what types of texts are absent from literary stories about nursing homes and what types of people are missing from the rosters of nursing homes and other care facilities and services. People such as the four old Indigenous patients depicted in Thomas King's 1993 novel *Green Grass, Running Water* are excluded, feel excluded, and/or exclude themselves from residency in Canadian institutions.

Canada's Multiculturalism Policy was established in 1971 and (according to the current Government of Canada website) purports that "all citizens are equal" and "can keep their identities, can take pride in their ancestry and have a sense of belonging" (Government of Canada, "Canadian Multiculturalism"). However, King's text suggests that the needs of marginalized groups cannot be met by institutions and services that historically have been geared toward mainstream, dominantly white, and Judeo-Christian people.

*Green Grass, Running Water* is an important work of its time for the message it relays regarding Indigenous placement within white institutions and also for its rallying message to the Indigenous community. King's work, alongside that of other artists, has helped to draw attention from both Indigenous and

non-Indigenous readers to the critical issues facing Indigenous peoples.<sup>1</sup> The text offers readers an opportunity to imagine the feelings and the frustrations of living as an Indigenous person in Canada. King contrasts cultural attitudes, particularly in regard to race, religion, gender, aging, and care.

At the end of the decade in which King published *Green Grass, Running Water*, the Canadian government finally closed the last of the residential schools that had been established in the 1800s in order to assimilate Indigenous children into the new Euro-Canadian culture. Although King does not speak openly about the ongoing disagreement between the Indigenous peoples and the Canadian government regarding the schooling of Indigenous children, his text contributed to the political pressure that eventually resulted in the 2007 Indian Residential School Agreement, the 2012 report by the Truth and Reconciliation Commission of Canada entitled *They Came for the Children* (Government of Canada, *They Came* 1), and the 2008 formal public apology by Prime Minister Stephen Harper (Miller 2).

The forced residential education endured by a century of Indigenous youth and the consequent injury to Indigenous communities were front-page and festering issues in Canadian society at the time King wrote the text. *Green Grass's* story about the institutionalization of four elders continues to be relevant today because many elders are experiencing pain and disconnection when dealing with the non-Indigenous administration of their late-life care that are similar to what was experienced by the residential-school children of their own and previous generations.

Centralized data on the state of late-life care of Indigenous people in Canada is difficult to obtain because the provinces administer health care while the federal government administers Indigenous matters (Beatty and Berdahl 7). In a 2011 article, Bonita Beulah Beatty and Loleen Berdahl, whose work focuses on the western provinces, express concern that large numbers of Indigenous seniors are being forced to leave rural and northern communities in order to access health-care facilities and services where they are “essentially divorced from familiar contacts with family and community health systems” (2). Reports from care services on the Atlantic side of Canada are similarly negative. The 2010 publication of the Aboriginal Home Care Steering Committee of Nova Scotia introduces the findings of their Home Care on-Reserves Project by reporting that an “overwhelming message coming from the communities is that long-term care is something culturally not accepted and something [Aboriginal people] try to avoid” (5). The steering committee adds that most respondents felt that existing services could never be adapted to meet Aboriginal needs.

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**1** | King is of Cherokee and Greek/German descent. The author of this article is a third-generation Canadian of white Anglo-Saxon Protestant descent.

*Green Grass, Running Water* portrays a community's efforts to preserve and yet adapt its Indigenous lifestyle in a world dominated by non-Indigenous people, and it presents the relative challenges of living on and off the reserve. At the beginning of the novel, four elderly men escape from the mental institution that supposedly has been caring for them but that also has been isolating them from their own land and people. The novel suggests that while white culture sees four useless old men with dementia, Indigenous culture sees wise and capable old leaders who have the ability to transcend earth's limitations with their supernatural powers and provide leadership to their people. They leave the institution in order to resume their place as elders in the Indigenous community and "fix the world" (123). By allowing readers to see into the integrated and complex community of the Indigenous people in the story and to witness the respect afforded the four seniors, the novel suggests that white and Indigenous cultural differences are too great to expect or allow Indigenous elders to be cared for by white administrations. By extension, the novel suggests that white culture does not have the understanding or capacity to govern the Indigenous at all. When King's characters walk away from a hospital where the administrator has either cared for them or imprisoned them, depending on whom one asks, they are escaping not just from an institution but from the dominant Judeo-Christian culture that they believe is responsible for breaking their world (2).

The nursing-home-narrative genre in Canada tells stories about white straight people of Judeo-Christian and Anglo-Saxon descent living in nursing homes that they may or may not be willing to call home. King's text considers the people who have excluded themselves, have been excluded, or who have felt excluded from living in white institutional care, either because their ideology precludes residency or because they are deemed unentitled by typical care-facility cultures. King's endowing of the four protagonists with otherworldly attributes, his use of myths taken from Indigenous culture, multiple narrative voices, and postmodern reflexivity combine to create a fantastical, entertaining, yet thought-provoking text with both magic realist and oral narrative characteristics. However, race, and in particular Indigeneity, is his primary focus. King makes fun of all of his characters, including the Indigenous ones, but he sends cutting verbal barbs toward Western culture and its history of persecution of Indigenous peoples.

Through its escape narrative, the novel changes the four protagonists' roles from passive to active, metaphorically suggesting the wrongful imprisonment of Indigenous peoples in places like reserves, white misunderstanding of Indigenous knowledge, and the challenges Indigenous peoples have in attempting to remain true to their own identity while caged within a world run by white cultures and governments. Although the four seniors are at the centre of the plot, there are numerous story threads dealing with other characters. The entire

community of mythical and realist characters representing Indigenous peoples together acts as protagonist in conflict with white people and their culture. King's title references the US government's promise to respect Indigenous peoples' rights to their land "as long as the grass is green and the water runs." Bernholz et al. state that the source of this phrase is Article 5 of the *Treaty with the Comanches and Other Tribes and Bands*, dated 12 August 1861, which states that "[e]ach tribe or band shall have the right to possess, occupy, and use the reserve allotted to it, as long as grass shall grow and water run, and the reserves shall be their own property like their horses and cattle" (1). Patricia Linton has aptly explained that the "title of the novel is itself a metonymic allusion to the bad faith that separates Native and European Americans. It is a coded reminder of a history of appropriation and the instability of European intentions" (217). King tells an amusing story about four Indigenous elders who escape from a white institution and return home to their land, to their rightful position, and to the embrace of their own community, but he also writes of a dark truth and the deeply felt desire of real-world Indigenous peoples to hold members of white culture to their promises.

Linton argues that the novel requires that "the truly competent reader is a member of a narrow group who, like the narrator, has insider-status in two cultural realms" (214). The non-Indigenous reader can appreciate many aspects of the text, but King makes exclusion clear by such techniques as the insertion of chapter headings in Cherokee<sup>2</sup> with no translation readily available.<sup>3</sup> The text's intriguing complexity has prompted a flurry of illuminating critical interpretations.

The plot of the novel is, to say the least, complex. As Greg Bechtel writes, there are "two distinct narrative streams within the text: a realistic, linear story of contemporary Blackfoot characters in an identifiably real-world setting, and a series of four Native myths that initially appear unconnected to the realm of the everyday" (1). The four old men participate in both narrative streams, thus connecting all the stories and indicating a comfortable and ongoing coexistence of material and spiritual worlds. When interviewed by the authorities following the elders' disappearance, mental institution employee Babo insists that they are "four, five hundred years old" (51), which suggests that, while they exist in the novel's real world, they also incorporate ancestors from the spirit

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**2** | The copyright page indicates that the "part title calligraphy" by Chris Costello is in the Cherokee language.

**3** | Linton also argues that the text seems evasive to many because it addresses "at least four different categories of readers with some claim to insider knowledge," and any one reader would require knowledge of all four fields in order to access it fully. In brief, these categories are Indigenous people, feminists, Canadians, and literary and historical scholars (226).

world who walk alongside their descendants on earth and continue to provide them with assistance, a common trope in Indigenous cultural productions and a significant factor in Indigenous religions.

These four elders take turns narrating various versions of the stories along with the trickster Coyote and a sixth narrator referred to only as "I," effectively suggesting Indigenous oral storytelling traditions. The four old men lampoon historical accounts, creative literature, and Judeo-Christianity while assuming the names of four white male heroes of Western culture: the Lone Ranger, Ishmael, Robinson Crusoe, and Hawkeye (9). The other narrative stream consists of creation-myth variations about four Indigenous women: First Woman, Changing Woman, Thought Woman, and Old Woman (39, 104, 232, 328). King's blending of the two narrative streams unites the mythical stories of the distant past with stories of the more recent past. The eventual blending of the narrative streams into the new contemporary story suggests a similarity between residency in the mental hospital and incarceration in Fort Marion, a prison in Florida to which the US army sent any Indigenous "leaders opposed to the reservation system" in 1874 (18, 397). The novel's combining of the image of the hospital and the image of the prison metaphorically suggests that Indigenous peoples feel a type of imprisonment living within white society.

The eventual juxtaposition of the narrative streams also blends the identities of the four old men into those of the four women. When interviewed by Sergeant Cereno about the "escapees" from the hospital, employee Babo reports that "they were women, not men," disputing his claim that the "files say the Indians were men" (53). This inconsistency contrasts white privileging of written fact and Indigenous privileging of oral knowledge and the flexibility of its truths. It also suggests that the old women may have been attempting to masquerade as men, which in turn references the exacerbated injuries that can result when people's identities involve multiple layers of otherness, such as being Indigenous, female, and old. The text references the felt need by Indigenous people to attempt to "pass" or survive within white culture by denying their heritage and pretending to be something acceptable to white society. Readers could also interpret this confusion over identity as referencing an inability on the part of white culture to accurately perceive the Indigenous, or they could alternatively interpret an elusiveness or preference for vague representation on the part of the Indigenous. Or this confusing portrayal could be a deliberate attempt by King to challenge Eurocentric preferences for binaries. King's prose is merely suggestive in these areas.

Eventually, the four oppressed women/men and their mythical world merge with the real world when the renamed mental patients magically "fix the world" – at least a little – by intervening in the life of the Lone Ranger's misguided "grandson" Lionel, by helping their descendants to assemble again as a community at the Sun Dance, and by reversing some of the humiliation

felt by Indigenous peoples by, for example, using historiographic metafictional techniques such as refilming a movie battle to show the Indigenous warriors defeating cowboy John Wayne (125, 322).

In King's fictional world, the aged ancestors are not incompetent male mental patients but rather knowledgeable yet humble elders out to "fix the world." The four repeat this line a number of times: "We're not on vacation ... We're working ... We're trying to fix up the world"; "It's a lot of work fixing up this world, you know," said the Lone Ranger"; and "We are trying to fix the world" (123, 416, 418). Although they are presented in a humorous fashion and make mistakes, King indicates that they do have power to effect change. For instance, they talk to the trickster god Coyote and are granted his cooperation in starting an earthquake to get them to the other side of Big Muddy River (418).

The old men leave to "fix the world," but they also leave because the facility is a non-home that isolates them from their own Indigenous community. King lampoons white care options by creating the most powerful overbearing administrator of all.<sup>4</sup> He names the administrator "Dr. Joe Hovaugh," a play on the name Jehovah, thereby critiquing white care institutions by suggesting that Indigenous peoples are forced to live within a culture that is based on the Christian religion rather than on Indigenous spiritual traditions. King belittles Judeo-Christian mythology just as Judeo-Christians have belittled Indigenous mythology. The novel includes the following line at the beginning and again at the end, satirizing the Christian creation myth, replacing Jehovah with Joe Hovaugh sitting in a Garden of Eden facsimile: "Dr. Hovaugh sat in his chair behind his desk and looked out at the wall and the trees and the flowers and the swans on the blue-green pond in the garden, and he was pleased" (16, 425).

When he notes that the old residents are missing, Dr. Hovaugh consults with the physician, Dr. John Eliot, a character named after a famous missionary who attempted to convert the Indigenous to Christianity in the 1600s. Hovaugh and Eliot ineffectively muse that the old residents must be dead because "they should have died ... a long time ago" (47), thus making reference to the assumption of many that the Indigenous tribes would eventually die out or be assimilated into white culture. However, Dr. Eliot will not sign death certificates unless Dr. Hovaugh can produce four dead bodies: "What I can't understand is how they escape. And where do they go? Have you ever thought about that Joe? And why, in God's name, would they want to leave?" (48). Here the novel pokes fun at the common white assumption that white culture is superior to Indigenous culture and that surely Indigenous people must realize this truth. King makes it clear that most Indigenous people avoid admission to white institutions such as late-life care facilities, not just because they are made uncomfort-

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**4** | The "overbearing administrator" is a common trope in the nursing-home-narrative genre. See Life.

able due to the racist attitudes encountered there but also because they prefer their own culture and consider it superior to white culture.

King's character Babo Jones, an African American, has been Dr. Hovaugh's employee at the institution for sixteen years, suggesting that King has noticed how frequently white care facilities employ brown- or black-skinned people as workers. The novel suggests that, like the old men, Babo has had white culture thrust upon her. The name "Babo" references an African character who violently resists being made a slave in Herman Melville's "Benito Cereno," a story in which a captain and crew are overpowered by the Africans that they are transporting for the purpose of selling into slavery. The slave Babo "determined to kill his master, Don Alexandro Aranda, both because he and his companions could not otherwise be sure of their liberty, and ... to prepare a warning" (Melville 1107). King provocatively places this volatile character's namesake in the midst of Hovaugh's supposed Garden of Eden. Thus the text is asking how this institution can be seen as a god's ideal garden when there are obvious racial inequities between the management and the employee and inmates. By including the African-American worker Babo in the story alongside the Indigenous residents, King emphasizes the felt racial separateness of Indigenous and African-American peoples and what he considers to be the oblivious ignorance of elite white management. King points out that Indigenous and African-American people lack a respected place in this white institution, or in any white institution for that matter, and that therefore they would rather exclude themselves from white culture. He suggests that white care administrations remain largely oblivious to all the ways in which Indigenous needs differ from mainstream needs.

Discussion of appropriate venues and services for late-life care must extend into a discussion of each person's values, traditions, and prior sense of place. Currently, services are not extended equally to all Canadians because government-administered facilities generally provide care appropriate for the mainstream resident and thus do not cater to the differing needs of those on the margins. The nursing-home-narrative fiction published in Canada depicts homes inhabited primarily by relatively privileged, white Anglo-Saxon Protestant residents. In *The Other Sister*, Lola Lemire Tostevin depicts two Jewish residents, Lena Kohn and Daniel Browne, but in general, residents of white Anglo-Saxon descent are the norm in Canadian nursing-home narratives (see Life).

King makes it clear that Canada is not exempt from the charges of racism he has applied toward the United States. When Babo and Hovaugh cross the border into Canada to look for the old men, the border guard insists that "[a]ll personal property must be registered," thereby blatantly suggesting that Babo is property rather than a person. King then writes: "Babo looked at the American border station and then at the Canadian border station. 'Where did you say we were?' she said." King continues: "'Welcome to Canada' said the guard, and

she handed Dr. Hovaugh her clipboard" (237). The text thereby suggests that, despite Canada's touted policy of multiculturalism, a person with black skin can expect to be treated as property in Canada.

By placing this female African American as an employee alongside the old Indigenous male/female inmates in the institution and under the administrative leadership of the white male Joe Hovaugh, King aligns and speaks for the rights of oppressed Indigenous, old people, workers, African Americans, and women alike.

In an article entitled "Sometimes It Works and Sometimes It Doesn't": Gender Blending and the Limits of Border Crossing in *Green Grass, Running Water* and *Truth & Bright Water*, Suzanne Rintoul argues that King alludes to gender rights more broadly: "The four old Indians ... expose the instability of the gender boundaries as established in European and North American culture: they are women who transition almost seamlessly to male figures" (239). One might assume that King depicts the residents as simply switching identities from female to male, but the novel also reduces the distinct divide between maleness and femaleness, suggesting instead more flexibility in gender identity and generally championing LGBTQ rights. The novel's depiction of Moby-Jane's and Changing Woman's rejection of Ahab's tyranny in favour of a relationship with each other is evident as they swim away together (187).

Rintoul explains, however, that King's discussion of gender is related specifically to Indigeneity and should be understood as being distinct from any general Western understanding of LGBTQ issues. She writes:

The importance of avoiding a universalizing or simplistic approach to thinking about First Nations gender identity cannot be overstated here, particularly since King reminds his readers repeatedly of the interrelatedness of race and gender. As each of the four old Indians assumes the identity of a white colonialist man to circumvent imprisonment, King aligns masculinity with European racism, and femininity with First Nations subordination. This process emphasizes the inadequacy of language that treats gender or race as discrete entities. (241)

I might add that, while the category of gender seems slippery in this text, most of King's categorizations are elusive in regard to boundaries.

Rintoul continues by adding that "King's four old Indians both trouble and reiterate European gender hierarchies," but she also states that she does not by this position intend "to displace readings of the Indians as part of the trickster or 'two-spirit' traditions." She summarizes the novel's style by saying that, "in King's fictional worlds, we cannot attach solitary meaning to any phenomenon" (241). As established above, when King writes about four old Indigenous men in a mental hospital under the care of Dr. Hovaugh, he is depicting the oppression of Indigenous people by white governments and Judeo-Christian culture,



and he is also depicting four old men in a care facility who may also be four old women. I would add that the novel is saying all of that while also suggesting that those four old people are multiply or flexibly gendered.

For flexibly gendered Indigenous and for non-Indigenous LGBTQ individuals, living in a late-life care facility may be a frightening prospect, and many might prefer to avoid walking through the door. Where individuals may be marginalized because of more than one factor, such as when they are both gay and Indigenous, negotiating the prejudice within institutions becomes even more challenging. If residency were to be unavoidable due to health and economic reasons, some might retreat back into the closet, which would mean that they then would be unable to receive visits from those people who were important to them but who might cause them to be outed again.

A US-based advocacy group called Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE) states that “L.G.B.T. older people are twice as likely to be single, and 3 to 4 times as likely to have no children – and many are estranged from their biological families,” all of which results in greater need for external supports in late life (Services 1). In Canada, some LGBTQ-friendly late-life care homes are becoming available in major centres. In Toronto, for example, two non-profit (Drs. Paul and John Rekai Centre and Wellesley Central Place) and three municipally funded care homes (Fudger House, Kipling Acres, True Davidson Acres) currently advertise themselves on the web as friendly to the LGBTQ community (Toronto Nursing Homes 1). However, LGBTQ-dedicated services are less available outside of major centres.

Many aged people of a variety of descriptions remain without a suitable support network to help them manage outside of an institution, and many are justly frightened at the prospect of admission to a culturally unacceptable facility.

In *Green Grass, Running Water*, King depicts four old people who for a variety of reasons walk away from a facility administered by white culture and government. Although this novel was written in 1993, the issues King portrays surrounding Indigeneity, gender identity, and aging continue to be of relevance today. King’s text invites readers to think about intentional and unintentional segregation of late-life care. Canada must encourage and facilitate the building of more homes and services directed to the specific needs of the marginalized. Kindness and good government require that care agents attempt to learn about all of the aspects of home that have been significant in a senior’s life and try to duplicate those qualities within the care facility or service. Until multiculturalism becomes more than just a written policy, care agents must attempt to provide everyone with an environment in which they can, at the very least, feel safe.

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## **Love, Age, and Loyalty in Alice Munro's "The Bear Came over the Mountain" and Sarah Polley's *Away from Her***

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*Katrin Berndt and Jennifer Henke*

This chapter discusses two examples of Canadian literature and film that offer a progressive perspective on age by contemplating questions of loyalty and commitment in a lifelong romantic relationship challenged by the impact of dementia. Both set in a long-term residential-care home, Alice Munro's short story "The Bear Came over the Mountain" (2001) and Sarah Polley's film *Away from Her* (2006) focus on the continuities and disruptions that define the tropes "love" and "age" in contemporary Canadian society. An adaptation of Munro's story, the film not only addresses change but represents itself the idea of a productive connection between faithfulness and the creation of something new. In Munro's tale, this correlation is realized through the intimate "relationship between memory, fidelity, and adaptation, [... which] offers insights into how [being committed to one's partner] can adapt to changing conditions" (McGill, "No Nation but Adaptation," 98–99).

In addition to conceptual emphasis and setting, the film and story share their main themes, characters, plot, and the narrative sequence of events. They depict the life of Fiona and Grant, a married couple in their seventies, who are observed in their interactions before and after Fiona develops symptoms of Alzheimer's. After experiencing a series of increasingly frequent memory failures, Fiona decides to move to a long-term care residence not far away from their home. When Grant is allowed to visit his wife for the first time after the thirty days' settling-in period, she cannot remember who he is. Moreover, she has become the companion of another patient, a physically paralyzed man named Aubrey who watches her conversations with Grant with undisguised jealousy. When Aubrey, who is only a temporary resident, is taken home again by his wife, Fiona develops symptoms of depression: she refuses to eat and spends much of her time crying. Grant's attentions make no difference to her. After a few weeks, the management considers moving her to the closed ward,

where patients are cared for who no longer participate in the shared activities of the residence. To prevent this, Grant persuades Aubrey's wife, Marian, to return him to the institution for good. The story ends with Grant announcing Aubrey's return to Fiona, who suddenly recognizes Grant as her husband and acknowledges his loyalty to her. It remains unclear whether Fiona's rediscovery of her memory will last, and whether seeing Aubrey again will actually improve her condition.

Taking into account scholarly criticism of both works, this chapter discusses the structural interest of story and film in the values inherent in lifelong romantic commitment, which they view as depending on a balance between intimacy and emotional distance. On a discursive level, the progressive correlation between love and age is emphasized in the idea of adaptation and through the rendering of life as an ongoing narrative, which conveys meaning through changes of perspective, spatial relations, and varieties of narrative order such as analepsis and prolepsis. In addition, the article demonstrates that affection and dedication are represented through intertextuality and recurrent rhetorical schemes and tropes in the story, whereas Polley's film uses landscapes and space to illustrate the partners' struggle with the nature and form of their commitment. Both works of fiction insist on keeping love alive, suggesting that in old age, a reconsideration of the idea of loyalty might mark a new beginning.

## **HUMOURS OF LOVE AND LOYALTY: "THE BEAR CAME OVER THE MOUNTAIN" (2001)**

Alice Munro's short story features several notable aspects that have become identified with her work for which she was awarded the Nobel Prize for Literature in 2013. One of Canada's foremost writers for several decades, her short stories have been unobtrusive yet highly articulate and valued contributions to the Canadian canon since the publication of her first collection, *Dance of the Happy Shades* (1968), which earned her Canada's most prestigious literary distinction, the Governor General's Award. Born as Alice Ann Laidlaw in 1931 in Wingham, Ontario, Munro grew up on a farm in Huron County. She studied English and Journalism at the University of Western Ontario and published her first story in a student magazine. Her work to date includes fifteen original collections of short stories and several television scripts. In the 1990s, she settled down in Clinton, Ontario, where she continues to live.<sup>1</sup>

Many of Munro's stories describe the challenges and relationships of "women of her own generation," who become adults after the Second World

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**1** | Detailed overviews of Munro's life and comprehensive discussions of her work can be found in Howells; Thacker; and Staines.

War and struggle to balance their longing for personal and professional independence with emotional intimacy (McGill, "Alice Munro," par. 18). The security that marriage and family seem to promise is challenged in Munro's writing, which studies the myriad ways in which unfulfilled desires, disillusionment, and discontent invade and undermine the stable framework of social convention. Munro's narratives are microcosms of Canadian lives in the twentieth century: they explore female opportunities in a patriarchal world, socioeconomic transformations, mother-daughter relationships, the vagaries of marriage and friendship, rural upbringing, (the mystery of) love, and the barriers of communication between individuals and within communities. Munro's preferred setting is rural Ontario, which shows an autobiographical influence on her writing, as does her dealing with themes such as the loss of parents and of children: her mother passed away comparatively young after having had Parkinson's disease for 20 years, and one of her own daughters died shortly after birth (Thacker 147, 125).

Several of Munro's stories are arranged in a cyclical pattern, which portrays events in the life of the protagonist at different stages and so combines elements of the story collection and the novel (Nischik 199). The cycle also draws attention to continuations and disruptions in characters' lives and indicates the intertextual and metafictional quality of subjective approaches to experience, memory, and the subsequent reinterpretation of both. Munro has shown interest in historiographic metafiction, a postmodern form of narration, which sheds light on how fiction is created and, in so doing, on how a story becomes a subjective account of history (see Duncan 27, 130-31). According to Canadian critic Linda Hutcheon, metafiction is a "process of creating order through myth and art," which gains historiographic significance when it is "grounded in historical, social, and political realities" (Hutcheon, *Canadian Postmodern* 2, 13). In "The Bear Came over the Mountain," sociocultural transformations such as sexual liberation and second-wave feminism in the 1960s and 1970s, respectively, form the background to the main character Grant's reflection on his life. The free indirect discourse of his memory reveals the associative and cognitive limits of his recollections, characterizing him as both nostalgic and self-involved. The story observes his reminiscing, though without passing judgment: Isla Duncan stresses that in Munro's writing, memory "is not always seen as a source of guilt or a reminder of disappointment"; the self-conscious re-creation of one's life "can sometimes be a means of escape, even a shelter," and as such it discloses "the interplay between characters' past and present lives" (103). Munro's figurative language and rhetorical means reflect her interest in what is, what has been, and what could have been: her allegories, allusions, paragrams, enumerations, and similes construct scrupulously detailed versions of ordinary life replete with hidden meanings, unsolved mysteries, suppressed desires, and secrets kept and revealed. The fictional lives she conjures up do

not necessarily follow a particular trajectory, as she explains in an interview: "I don't take up a story and follow it as if it were a road, taking me somewhere, with views and neat diversions along the way. I go into it, and move back and forth and settle here and there, and stay in it for a while. It's more like a house" (McCaig 93).

And just as it takes a while to feel at home in a new place of residence, Munro's stories require more than one reading to become familiar with all their hidden nooks and crannies. This is certainly the case with "The Bear Came over the Mountain," which was first published in her collection *Hateship, Friendship, Courtship, Loveship, Marriage* (2001). Gradually revealing the self-involved quality of the main character's view on his marriage, the narrative investigates the form that love assumes when one partner suffers from a degenerative disease. The story is one of several in Munro's 2001 collection that address the endurance of both love and commitment under circumstances such as misfortune, adversities, and a variety of severe strokes of fate: apart from what appears to be Alzheimer's in "The Bear Came over the Mountain," the collection's contributions deal with infertility, cancer, and suicide. As a reviewer points out, however, "in none of these stories do things go from very bad to worse" (Pritchard, par. 5). Munro is more interested in exploring what such afflictions can unearth and encourage in people's thinking and in their attitudes toward one another than in indulging in elaborate, emotive renditions of human suffering.

The revelations disclosed by Fiona's degenerative disease revolve around the couple's marriage and their life together, which, according to Grant, was a fairly good one, "without too much going wrong" (Munro 306). Told from a third-person perspective, the story is seen through his eyes, an unusual focalization in Munro's work, which more often features the point of view of female protagonists. In contrast to many of her women characters, Grant does not want intellectual or professional independence, both of which he has always enjoyed: he struggles to remain emotionally close to his wife although she has forgotten the life they once shared. His efforts slowly reveal that even before Fiona's illness, their relationship had been characterized by a careful balance of distance and intimacy that has enabled her in particular to retain her dignity during Grant's extramarital affairs. Grant's apparently noble and selfless gesture – his efforts to organize Aubrey's return to the residential home to stabilize Fiona's health, even at the cost of her being the companion of another man – appear as an attempt to make amends for betraying her in the past. According to Robert McGill, Munro's story "explore[s] the very question of what it means to be faithful" when it integrates "Grant's own possible adultery ... into the project of seeking Fiona's well-being, so that in the story, adaptation and infidelity seem to go hand in hand as activities necessary for happiness" ("No Nation" 100, 101).



The story uses a combination of intertextual references and shifting narrative modes to portray both Fiona and Grant's love for one another and the tension between dedication and distance in their relationship. Particularly interesting for a narrative that explores mature romance in a care home is that the title of Munro's story is an adaptation of a North American nursery rhyme, an oral genre associated with childhood. The rhyme "The Bear Went over the Mountain" mocks an adventurous bear in repetitive verses and produces an odd contrast to the themes of the story:

The bear went over the mountain,  
The bear went over the mountain,  
The bear went over the mountain,  
To see what he could see.  
And what do you think he saw?  
And what do you think he saw?  
*The other side of the mountain,*  
*The other side of the mountain,*  
*The other side of the mountain,*  
*Was all that he could see.*  
(Ventura 174)

In her analysis of Munro's intertextual references, Héliane Ventura suggests that the rhyme is merely a "self-parodic play on words, which relies on the opening up of expectations only to frustrate curiosity with the platitude of a tautological closure," because "[t]he world that the bear discovers is just as ordinary as the one he has just left" (174, 175). The rhyme introduces into the story the "tradition of 'Nonsense' as evidenced in the writings of Lewis Carroll and [Edward] Lear" in order to mock "all our expectations of heroic aggrandizement and magic discovery" (175). Such parody suggests reading Grant's behaviour as essentially self-serving rather than self-sacrificing, which is supported by the story's indication that he begins an affair with Marian, Aubrey's wife.

In the figurative context of Munro's story, however, the emphasis of the rhyme lies on the shift of situation and perspective, which in itself is the discovery of something extraordinary. This interpretation is confirmed by the author's choice of words: in contrast to the original nursery rhyme, Munro's "bear" does not go "to see what he could see"; he *comes over* the mountain, a different verb which suggests a deliberate advance to somebody rather than the mere following of a curious impulse. Moreover, given Grant's previous adultery, it is not self-evident that he would not "go," that is simply leave his wife now that she has forgotten him, but that he decides to "come over," to make an effort to approach Fiona in order to remain emotionally close to her. "On

the other side,” he then finds himself surprised “to see what [s]he could see.” His wife’s condition compels him to move to the other side, where he begins to consider her view of him and his actions. This shift is involved in another meaning of *coming over*, which denotes a change of allegiance: forced by Fiona’s illness to assume a new perspective, Grant is not only given the opportunity to view their life together from his wife’s point of view; the accompanying realization also gives him the chance to show loyalty to her, and to his feelings for her. Reading Grant as “the bear” who comes over to the other side *grants him* a change of view on their marriage and the subsequent opportunity to commit himself to her well-being.

The new perspective conveyed by the connotations of the title corresponds with the changing focus in the narrative mode: on the morning before Grant visits Fiona for the first time, he experiences a “tingling” of anticipation that announces his “expectation of discovery,” which is contrasted with feelings of “timidity, humility, alarm” (Munro 287, 288). In the residence, the narrative shifts from sharing Grant’s sensations to reporting his meticulous observation of the care home as well as the people and activities he encounters there. This enumeration of spatial and individual details serves several purposes. Sara Jamieson has pointed out that in contemporary Canadian fiction, residential-care homes are no longer represented solely “as institutions to be avoided or escaped,” and that Alice Munro’s stories in particular portray “the old age home in a way that turns a critical eye to its disadvantages, yet also remains open to how those disadvantages might be mitigated and a habitable existence sustained” (2). Grant’s observations in “The Bear Came over the Mountain” illustrate this aspect: the generous design and bright atmosphere of Meadowlake painstakingly avoid any association with enforced placement but instead illustrate his desire to see the elderly inhabitants comfortably located in what is now their home: “[The nurse] led him along a hall, into the light of the huge sky windows in the large central space, with its cathedral ceiling. Some people were sitting along the walls, in easy chairs, others at tables in the middle of the carpeted floor. None of them looked too bad. Old – some of them incapacitated enough to need wheelchairs – but decent” (Munro 289). When he finally sees Fiona, however, his emotional response to the place alters. Grant continues his detailed description, noticing the changes in his wife’s clothes and her hair, but now his observations reveal his confusion. Her new home is no longer his, and he will soon get lost in the residence, literally and emotionally: “On the other side of the mountain,” he suddenly finds himself alone in their marriage. Being with Fiona now includes the feeling of being away from her: “He could not throw his arms around her. Something about her voice and smile, familiar as they were, something about the way she seemed to be guarding the players and even the coffee woman from him – as well as him from their displeasure – made that not possible” (290). When he encoun-

ters the changed Fiona in the care home, Grant's feelings are rendered mute, leaving a blank space, an intimate omission that is resolved only at the very end of the story.

In his attempt to fill the emotional void that Fiona's disease has created, Grant looks back on their life together; he recalls their first encounter, the particularities of their marriage, and his repeated unfaithfulness to his wife. In typically ambivalent Munro fashion, Grant's reminiscing about his affairs emphasizes both his love for his wife and his lack of consideration for her feelings at the time. The independence he enjoyed has included betrayal. It is another characteristic of Munro's writing, however, that the reader can never be sure that Fiona even knew about Grant's affairs, or if she did, whether she was bothered by them. The narrative focuses exclusively on Grant's perception, which presents him as a philanderer who took advantage of the promiscuous opportunities of the late 1960s. In the story of their marriage in these years, Fiona is presented only through his eyes; her feelings and opinions are presumed only, and through his memory:

A whirlwind hit him, as it did many others, wish becoming action in a way that made him wonder if there wasn't something missed. But who had time for regrets? He heard of simultaneous liaisons, savage and risky encounters. [...] Academic parties, which used to be so predictable, became a minefield. An epidemic had broken out, it was spreading like the Spanish flu. Only this time people ran after contagion, and few between sixteen and sixty seemed willing to be left out.

Fiona appeared to be quite willing, however. Her mother was dying, and her experience in the hospital led her from her routine work in the registrar's office into her new job. (302)

While Grant is happy to run with the crowd, Fiona starts working as a "hospital coordinator of volunteer services (in that everyday world, as she said, where people actually had troubles that were not related to drugs or sex or intellectual squabbles)" (287).<sup>2</sup> He takes note of the fact that she appears to be uninterested in sexual encounters with others, but he does not question her "unwillingness." Moreover, his own retrospective view characterizes him as a narcissistic

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**2** | Robert McGill discusses Munro's ambivalent portrayal of sexual liberation as a feature of her general skepticism toward historical progress: "Munro's stories set during the 1960s and '70s, in particular, suggest that for all that was accomplished by the Women's Liberation Movement with regard to things such as divorce laws, abortion rights, and the availability of contraception, society has remained fundamentally sexist in important ways. [...] In 'The Bear Came over the Mountain', Munro characterizes the era of 'free love' principally as a time in which husbands became freer to cheat on and leave their wives" ("Alice Munro and Personal Development" 147).

man<sup>3</sup> who only regrets that he missed the signs of the times at the dawn of second-wave feminism, when his approaches to his female students were no longer considered welcome:

The shame he felt then was the shame of being duped, of not having noticed the change that was going on. And not one woman had made him aware of it. There had been the change in the past when so many women so suddenly became available ... and now this new change, when they were saying that what had happened was not what they had had in mind at all. ... All so that he could now find himself accused of wounding and exploiting and destroying self-esteem. And of deceiving Fiona – as of course he had deceived her – but would it have been better if he had done as others had done with their wives and left her?

He had never thought of such a thing. He had never stopped making love to Fiona in spite of disturbing demands elsewhere. He had not stayed away from her for a single night. (286)

Congratulating himself on the uninterrupted continuity of his sexual performance, Grant takes up a phrase that is used at the beginning of the story, and which also becomes the title of Polley's film. The young Fiona proposed to Grant with the words, "Do you think it would be fun if we got married?," and he realized then that he "wanted never to be away from her. She had the spark of life" (276). And while he made sure indeed not to spend nights *away from her*, the ways in which Grant has actually *been with* his wife are conspicuously absent from his narrative. He recollects neither caring for her during her mother's decline nor being sympathetic at the news that Fiona cannot have children: "Something about her tubes being blocked, or twisted – Grant could not remember now. He had always avoided thinking about all that female apparatus" (279). His lack of regard suggests that the "fun" she was having with him had been morphed into puns, irony, and comic paragrams that allowed Fiona to share her life with Grant while keeping him at an emotional distance. He does not question her use of humour before the disease breaks out; Grant sees Fiona as a "direct and vague, ... sweet and ironic" (277) woman, whose apparent indifference toward his affairs places him in the comfortable position of never having to justify himself.

It is only Fiona's illness that eventually confronts Grant with his repressed but lingering uneasiness about this blank space in their relationship: did she

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**3** | "Grant is represented ... as a narcissistic and egomaniac philanderer [... who, in spite of] his having had a great many affairs, ... has never left Fiona and the final act he indulges in acquires an ambiguously redeeming dimension" (Ventura 179). Grant's narcissism is also illustrated by the Narcissus flowers he buys for Fiona upon his first visit in the residential-care institution (McGill, "Mistaken Identities" 71; Munro 288).

know about his unfaithfulness, he wonders, and does she now play “some kind of charade” (294) in order to punish him? After all, Fiona’s verbal games are so much a part of her personality that her memory loss in the residence might be merely another one of her frequent jokes:

He could not decide. She could have been playing a joke. It would not be unlike her. She had given herself away by that little pretense at the end, talking to him as if she thought perhaps he was a new resident.

If that was what she was pretending. If it was a pretense. (292)

Over the years of their marriage, Grant has become used to Fiona’s playfulness; sharing puns even became part of their routines as a couple. Fiona’s illness and Grant’s subsequent change of perspective forces him not only to accept that she is no longer joking – it also confronts him with the possibility that her humorous comments in the past were not meant to be funny, after all. Ironically, Fiona’s dementia unearths the unreliable “memory on the part of the supposedly rational, healthy, and normal care provider” (Goldman and Powell 85). In order to adapt to the new situation, Grant now has to reconsider his established knowledge about their marriage; his failure to “read” his wife in the present initiates his recollection of a past in which he already might have misunderstood her. Grant’s new perspective – his adaptation to the changing circumstances of his commitment to Fiona – confronts him with his own dormant feelings of guilt and, eventually, with his continued penchant for flirtatious games and amorous manipulations.

In two further ironic twists of romantic commitment, Grant has to secure his wife’s well-being by organizing Aubrey’s return to the residence, which involves Aubrey’s wife Marian’s cautious attempt to initiate some form of relationship with Grant. Her advances lack any tender appeal: during their conversation, she makes it clear that placing Aubrey in the care institution permanently would render her homeless and without financial provision. When she calls Grant to suggest a social meeting, she indicates a solution that would grant both of them what they want. However, in so doing, Marian reveals insecurity and want, something that calls forth Grant’s old habits of erotic scheming and manoeuvring:

It gave him satisfaction – why deny it? – to have brought that out in her. To have roused something like a shimmer, a blurring, on the surface of her personality. ... Anything was possible. Was that true – was anything possible? ... It would be a challenge. A challenge and a creditable feat. Also a joke that could never be confided to anybody – to think that by his bad behavior he’d be doing good for Fiona. (320)

The sequence of events absolves Grant to an extent, for he had contacted Marian first in order to persuade her to allow Aubrey return to the residence for Fiona's sake. Nevertheless, Grant indulges in the knowledge that Marian might be attracted to him, and considers triumphantly ("a creditable feat") the prospect of an affair with her.

Munro conjures up a wonderfully intricate net that intertwines her characters' different fictions of their intentions when she combines Fiona's longing for Aubrey with Grant's willingness to ensure her happiness and his relapse into his philandering past. His wife's loss of memory, her weakened condition and depression, which had provided Grant with the chance to show some disinterested motivation himself, puts him in a situation that seems to give him not only the moral right, but the obligation to be unfaithful again. In fact, he is being rewarded for being loyal with the prospect of another infidelity. This portrayal of mature romance in a nursing home "juxtaposes the sublime and the farcical, the weird and the noble, the heretic and the pragmatic, on the threshold between life and death, in a senior citizen's residence" (Ventura 179). The story presents love in the winter of life without any "pathos and self-pity in order to favour a playful, distanced, and ironic approach to the ravages of aging" that pursues nothing less than a reconsideration of the essential meaning of commitment (Ventura 174). To be dedicated to somebody, the story suggests, is an ongoing process of transformation and adaptation to new situations and challenges. This understanding of mature love as progressing still allows the characters to ignore, for the time being, what is otherwise associated with old age: loss of self, deterioration, and death. At the end of Munro's narrative, Fiona and Grant refuse to let their marriage come to a close: for a brief moment, in their final encounter, they celebrate their love, allowing themselves to enjoy the possibility of a shared future.

The last scene shows them alone once more in Fiona's private room in the retirement home. Suddenly recognizing Grant as her husband, Fiona's habitually ironic mode becomes charged with a melancholic acknowledgement of their past and their present situation, as she resorts to another paragram and takes into tender account Grant's decision to *come over* to his wife after all: "You could have just driven away [...] Just driven away without a care in the world and forsook me. Forsooken me. Forsaken" (Munro 323). Grant responds to her return to their playful mode with another enumeration of her features, listing them like the details of the residence upon his first visit, but now with a regained sense of familiarity, which indicates his feeling at home, now, with her, on the other side: "He kept his face against her white hair, her pink scalp, her sweetly shaped skull. He said, Not a chance" (323).

## SPACES OF LOVE AND AGE: *AWAY FROM HER* (2006)

The idea of shared life and love as a journey that continues even after one of the partners relocates to a care home also features in Polley's film, whose promotional tagline claims that "It's never too late to become what you might have been."<sup>4</sup> The second part of this chapter turns to Sarah Polley's cinematic appropriation of Munro's short story to address notions of adaptation, love, and age, as well as space and care. It focuses particularly on how the film continues Grant and Fiona's story in the new spatial context of the nursing home and the necessary changes of perspective that long-term residential care involves.

This section illuminates the key issues of love and age by extending a reading of these themes to a cinematographic level. In addition, it sheds light on the director's motivations to adapt Munro's short story and discusses the actual meaning of loyalty (McGill, "No Nation" 100). During the following analysis of selected film scenes, the notion of space as a carrier of meaning looms large as it contributes to the understanding of both pre-text and adaptation in terms of love, age, and care.

*Away from Her* (2006), a movie about an elderly couple confronted with a geriatric disease, is the debut film of Canadian director Sarah Polley, herself aged only 27 at the time it was released. When asked in an interview by Brian D. Johnson about "what drives a woman in her 20s to devote her feature directing debut to a story of old folks losing their grip" (Johnson, par. 2), Polley indicates that she first read Munro's short story at the age of 21, freshly in love with her future (and now former) husband. She adds: "I was shell-shocked. I found it so moving ... It just sat there for a couple of years ... this vision of a film that wouldn't go away" (par. 1). The last word of Polley's reply already alludes to the movie's title and its intrinsic semantics of intimacy and distance. At the same time, it raises the questions of who moves *away* from whom, why, and how. Further, what role do love and age play in this context?

According to Polley's statements, she instantly fell in love with Munro's short story. She blamed her enthusiasm on young love and her own budding relationship with the film editor of *Away from Her*, her first husband David Wharmsby: "The idea of a long marriage became fascinating to me. ... What does [love] look like after decades – after you've failed each other? That became so much more interesting to me than a traditional love story about people when

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4 | McGill, "No Nation" 109. The quotation "It's never too late to be who you might have been" has been attributed to George Eliot since the nineteenth century, but it is not contained in any of the writer's publications (Mead); the phrase is also the title of a motivational publication (Gallagher). The slightly modified "It's never too late to become what you might have been" is the title of a song about "sinners with the best intentions" by the US band Cities Never Sleep.

they're young and dumb and boring" (Johnson, par. 3). What also drove Polley to produce this film was a biographical fate she shares with Alice Munro: both lost a close relative at a very early age. When Polley was 11, her mother died of cancer. Similarly, Munro had to face her mother's diagnosis with Parkinson's disease at the age of 10 and nursed her for another 18 years.<sup>5</sup> Moreover, in her 20s Polley had to experience the illness and death of her maternal grandmother, who suffered from Alzheimer's (Casal 136). Both Munro and Polley are therefore very familiar with what it means to care for an ill or old relative. It is very likely that the film production helped Polley cope with her experiences, as McGill ("No Nation" 105) and Sally Chivers (86) point out.

Polley's childhood and younger years were exceptional for further reasons. Born in Toronto in 1979, she was in contact with the film industry at the age of four, signed up for her first movie when she was six, and quickly developed into a child star who featured in various Canadian series, Disney films, and other international movies. After dropping out of school at 14, she moved into her own apartment and became engaged in left-wing politics for some time. Polley returned to the screen in the late 1990s and starred in numerous Canadian and Hollywood movies, many of them independent productions. Her debut film *Away from Her* received two Oscar nominations for best leading actress (Julie Christie) and best adaptation. Polley has produced two more Canadian feature films so far: *Take This Waltz* (2011) and *Stories We Tell* (2012), the latter a documentary about her own family. Interestingly, all three films negotiate questions of love, age, memory, shifting perspectives, adaptation, and fidelity. Polley is currently producing the CBC miniseries *Alias Grace*, an adaptation of the award-winning novel by Margaret Atwood, which will be released globally in 2017.

With regard to the question of who adapts to whom, why, and how, McGill has argued that Polley's *Away from Her* is not only an adaptation but also a "text *about* adaptation" ("No Nation" 99; emphasis in original), which "aligns adaptation with love" (100) on several levels of meaning. Not only does Polley artistically adapt (to) the source text out of love for Munro's short story on an extratextual level, but the fictional characters of the film themselves are also confronted with notions of memory, fidelity, and the necessity to which they have to adapt. In fact, the film's plot mirrors the process of artistic adaptation in a particularly striking manner. After Fiona's diagnosis, the couple adapt to their new situation and environment in a similar way in which the filmmaker Polley adapts to the source text: both disregard notions of fidelity. According to Linda Hutcheon's adaptation theory, "faithfulness" – that is, fidelity criticism –

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**5** | The personal difficulties of nursing a relative with Parkinson's disease are also reflected in Munro's short story "The Peace of Utrecht," published in *The Dance of the Happy Shades* (1968) (Albertazzi 5).



is an outdated concept (*Theory* 6–7). Instead, Hutcheon regards adaptations as “ongoing dialogical process[es]” (21)<sup>6</sup> between pre-text and adaptation in which neither is valued over the other. On a discursive level, the same holds true for Grant and Fiona as well as for Polley. However, the more the adapter attempts to adhere to the “original,” the less likely she or he is to succeed. Hutcheon proposes “repetition with variation” (4) as the key factor in an adaptation’s effectiveness, as it is the play with memory and deviation that evokes pleasure in the audience. Similarly, Grant has to adapt to the new situation in the residential home by continuing to care for and thus remain “faithful” to Fiona. His deviation is stronger in the film version, as Polley explicitly depicts him having an affair with Marian (Olympia Dukakis). Nevertheless, Grant can achieve his own personal loyalty to his wife only by shifting his perspective and transforming from “jealous husband to procurer of romance for Fiona” (McGill, “No Nation” 100).

The movie’s title, which differs from the one Munro chose for her short story, already offers a variety of readings in terms of changing perspectives. While Grant (Gordon Pinsent) can be identified as the “bear” who needs to “come over the mountain” and thus shift his perspective, the film’s title is a direct quotation of one of Grant’s early memories of Fiona (Julie Christie) (Munro 276) but is somewhat equivocal. Whereas Munro’s title raises the questions “what bear, what mountain?,” Polley’s choice makes the audience wonder “who is she?” and “who is the one moving away, why, and how?” On a diegetic level, the suggested spatial relation of this title refers to Grant’s unfaithfulness during their marriage. Further, it alludes to Fiona’s abandonment of Grant after she moves into the care institution and forgets who he is. It can also be read as Aubrey’s (Michael Murphy) departure from the nursing home that triggers Fiona’s severe depression and subsequently leads to Grant’s decision to support their reunion. Against the backdrop of artistic adaptation, McGill stresses the “necessity [of] certain infidelities within the parameters of a broader loyalty to the original text” (“No Nation” 102). Like Grant, Polley needs to detach from her love object (Munro’s short story) in order to remain “faithful.”<sup>7</sup> The director has to avoid mere mimicry as it would inevitably lead to artistic failure (Herrera 108). Thus, for both Polley and Grant the lines between fidelity and infidelity become blurred. The filmmaker achieves her

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**6** | By referring to Amelia DeFalco, Jamieson likewise points to “aging as a process” (2), which in turn can be regarded as a form of constant adaptation to new situations and surroundings.

**7** | Ironically, the German translation of the movie title reads *An Ihrer Seite*, which means “by her side,” a phrase that lacks the semantic ambiguity of the original. On the other hand, the German title corresponds to the paratexts of the movie – namely the DVD cover and poster – which depict the loving couple in intimate proximity.

goal to produce a successful adaptation not only by adding new scenes that slightly alter Munro's plot but moreover by her clever use of "a wide range of cinematic devices" to "mirror Munro's disruptive chronology" characterized by Grant's memories or flashbacks (Herrera 109, 113). The transfer of Munro's narrative into a visual medium is one of the key advantages of this adaptation, as "memories materialize, become images" on the space of the movie screen, as Agnès Berthin-Scaillet points out (2). It is arguably the case that Polley is to the film what Grant is to Munro's story: the bear who must "come over the mountain." The young filmmaker has to shift perspective in order to "survive" artistically when dealing with a long-term love relationship of an elderly couple confronted with the necessity of residential care.

This change of perspective is apparent also on a cinematographic level, and the discussion will now turn to showing how the film text constructs Grant's transformation from jealous partner to provider of love and care for Fiona, a shift occasioned by his wife's relocation to the care home. The analysis focuses on different aspects of space as carriers of meaning and it will demonstrate that space itself, as a product of culturally coded signs, can fulfill a symbolic function. Movements through space, for instance, not only by characters but also by the camera, contribute to the meaning of a text. Physical spaces can likewise be read symbolically and thus extend the interpretation of a narrative. Further, the use of light and colour creates an atmosphere that functions as a reflection of the protagonist's mood or general state of mind. With regard to the shift in perspective, the analysis will particularly focus on *spaces of transition*, which include certain locations such as cars, snowy landscapes, homes, care homes, beds, and corridors that are symbolically enhanced and contribute to realize the change in perspective on an audio-visual level.

Polley's movie begins *in medias res* with a medium shot of Grant driving through a housing estate in his car on a winter's day. The camera pans to the right and displays a note in his hand, on which is written Marian and Aubrey's home address. Shortly after, the camera pans back to Grant's face and then fades to a greyish and grainy close-up of a young, blonde, smiling woman – Fiona. She is shot in front of what seems to be a seashore. In a voice-over we hear Grant's voice recalling: "She said, do you think it would be fun if we got married?" A female voice asks: "Then what did you say?" Grant replies off screen: "I took her up on it. I never wanted to be away from her. She had the spark of life." After this conversation, the young woman's lip movements indicate the sentence "What do you think?" Finally, the camera fades to white (*Away from Her* 00:00:00–00:01:07).

Grant's movement in his car through the housing estate echoes former events that will be narrated in retrospect as the movie proceeds. The way he moves around in his vehicle, seemingly disoriented and relying on a note he holds in his hand, recalls how Fiona relies on notes she sticks to things in

their house before she moves to the old-age home Meadowlake. Grant's car thus functions as a vehicle or (meta-)space of transition: he is on his way to Marian in order to ask her to move Aubrey back to the nursing home and is hence forced to change his perspective on love, age, and the notion of loyalty. It is in this space (the car) that he is actively about to "come over the mountain" right from the film's exposition. The subsequent fade to Grant's memory of Fiona further aligns love with time or age and interconnects the past with the present. The juxtaposition of Grant's elderly complexion with the image of Fiona's younger self combined with her playful question regarding their engagement indicates one of Grant's "cheerful" flashbacks. Recalling Berthin-Scaillet, Grant's memories materialize on the film screen. This constitutes the benefit of the medium as the words of the short story transform to images on screen. In Polley's movie the seashore functions as a spatial metaphor for both remembrance and the loss of memory, especially with regard to Fiona's deteriorating mental state, triggered by her dementia.<sup>8</sup> In terms of spatial metaphors, Fiona's depiction in front of a seashore amplifies the cinematographic effect of reminiscence; in this case it points to Grant's own perspective on his long-term marriage.

What follows after the final fade of the first sequence is a medium pan shot of two parallel tracks on a snowy surface. The camera then moves upwards and we see a two shot of a couple from behind who are following the tracks. The skiing characters, Grant and Fiona, then move away from the audience's perspective into the vast landscape. The next full shot depicts Fiona skiing to the left of the screen frame on her own tracks while Grant takes a slightly different direction in the background, only to join her again in the next shot. Both of them are reunited in their parallel tracks and continue to move toward a house in the distance. The scene ends with another white cross-fade and the inserts *Away from Her*.

Two aspects of this scene are remarkable: first, the dominance of snow, and second, Grant's temporary deviation from their common tracks. The snowy landscapes serve as a spatial leitmotif in the film; they appear at the beginning, in the middle and the end of the film, thus framing the narrative. Of particular importance in this scene is Grant's movement through space. Against the backdrop of love and age, his temporary deviation from the couple's common tracks serves a symbolic function on three levels: first, they visualize Grant's

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**8** | Chivers as well as Goldman and Powell identify these flashbacks as "ironic lapses in memory" (Goldman and Powell 85) with regard to Grant, who from now on can "settle into his unchanging ways" (Chivers 92) as a disloyal husband only wishing to care for his equally disloyal wife. According to Chivers, Polley uses Alzheimer's, a disease associated with old age, "as a metaphor for infidelity" (92; Goldman and Powell 91), thus aligning love, age, and loyalty on an audio-visual level.

former affairs with his students while never “leaving” his wife; second, they allude to his seemingly selfless distancing from Fiona by bringing Aubrey back to the nursing home; and third, they hint at his eventual return to their shared path (followed by the cross-fade and the inserts *Away from Her*), which expresses his faithfulness to Fiona. The visuals alone suffice to evoke the idea that a successful long-term relationship depends on a balance between intimacy and distance. Berthin-Scaillet emphasizes that “this ... series of shots dissolving into each other provides the choreography of the couple’s life in common, on a filmic scale” (5). Furthermore, the spatial metaphor just described also works on a discursive level, as Polley has to achieve a careful balancing between intimacy and distance, pre-text and adaptation, faithfulness and deviation. In Berthin-Scaillet’s words, she “successfully follows the tracks of Munro’s text” (3). Like Grant she needs to temporarily move *away from her* (i.e., Munro) in order to accomplish a successful and durable adaptation. Polley achieves this deviation by adding new scenes and deleting or maintaining others, thus adhering to the artistic rule of “repetition with variation” stressed by Hutcheon (*Theory*). In the end, both Polley and Grant remain faithful precisely because loyalty involves an occasional departure from the main track. However, this reading renders Grant’s actions selfless and altruistic whereas his behaviour is rather self-serving than benevolent. One important variation of Polley’s movie underlines this reading, as it shows Grant and Marian actually having an affair instead of him only fantasizing about it, as he does in Munro’s short story. The film depicts the two of them in bed in what seems to be a “post-coital embrace” (Goldman and Powell 90). Here, the bed functions as one of the film’s spaces of transitions and underlines the symbolic potential of spatial representations.

The first part of the movie displays the couple in their cottage in a medium two shot in an exchange of affection, Grant on the left and Fiona on the right side of the bed. The camera then fades to white and repeatedly displays Grant driving in a car on his way to Marian and Aubrey’s house (00:04:21–00:04:50). The bed scenes are reiterated throughout the film, but with variation: shortly after Fiona decides to move to the care home Meadowlake, the main couple is depicted in exactly the same two shot in bed, their backs turned to one another this time. While Grant sleeps, Fiona leaves the film frame, thus leaving the right side of the bed empty. In contrast to the previous skiing scene, she is the one creating a distance between the two (00:27:46–00:28:10). In a later bed scene during the last night they spend together in the residential home, Grant in turn exits the frame after Fiona tells him to “go now,” leaving an empty space on the left side of the bed (00:36:45–00:37:36). In the second part of the movie, Polley films Grant and Marian in a similar two shot in bed after the characters have evidently slept together (01:33:39–01:43:06). This time, however, Grant is situated on the right side, which can be read as an indicator that he has finally “come over the mountain.” For Berthin-Scaillet, these repeated shots and

sequences are to be interpreted as a kind of “inverted mirror image” in order to visualize the “feeling of estrangement from his wife that Grant has to cope with. ... Everything is repeated but inverted” (5). The beds of Grant, Fiona, and Marian thus function as spaces of transition: not only is Fiona never the same again after her husband leaves her in the nursing home, but it is here also that Grant finally *grants* his wife more free *space*. Beyond that, he literally fills his own empty space with a new lover. Grant’s (sexual) relationship with Marian is of particular importance to Polley’s artistic strategy. The images fill in the blank spaces of the pre-text: Munro’s short story only hints at a sexual relationship between Grant and Marian, while the film text materializes his fantasies.

Another metaphor representing love, loyalty, and age and the necessary shift in perspective is the opposition “home vs. care home.” To begin with, Grant’s and Fiona’s “home,” their house in the countryside, represents their shared memories. When Fiona sets out for a trip on her skis, this time alone, she gets lost in the snowy woods close to their cottage (00:14:49–00:16:07). The camera displays her in a frontal medium shot outside of their home, to which she turns, clearly confused, and then wanders off into oblivion. She later lies down in the snow, the camera shooting her from a bird’s eye perspective until the screen fades into the night sky. This scene serves as a turning point with regard to her deteriorating mental condition. The snowy landscape, combined with the camera technique, nicely illustrates the “blank page[s] of lost memory” (Johnson, par. 16). As Herrera emphasizes, “The movement of the camera, zooming over her as it circles down from above, adds to the sensation of utter loss” (115). There is a similar scene later in the film in which Grant is shot from exactly the same angle in front of their house (00:41:52–00:42:38). He, too, turns around to look at their home – a signifier of their marriage and memories – in an obvious example of remembering, while he compares Alzheimer’s disease in a voice-over to the extinguishing of lights: one by one the lights in Fiona’s mental space are switched off. More important, the fact that both Grant and Fiona are not skiing “along the perfect symmetry of parallel tracks” (Berthin-Scaillet 5) in these scenes, but moving through space separately, indicates their mental and emotional change in direction. As a result, the snowy landscape functions not only as a visual leitmotif for memory but also as a space of transition where the couple is forced to take on a new perspective on their relationship.

The final space that will be discussed is the nursing home Meadowlake. The residential home is divided into two levels: the first floor for patients who can still live relatively independently, and the second floor for those who are in need of constant care, who are lost and have “lost it” (Munro 299). It is this space “where residents transform into patients”: it ironically represents an “opposite movement” by which people ascend to an upper floor and are removed “from the public sphere and everyday life” (Adams and Chivers, par. 22). In Polley’s adaptation, Fiona is transferred to the second floor after her condition deteriorates and

thus simultaneously moves to another mental state, namely severe dementia paired with depression. The film text establishes a clear connection between the physical space of the old-age home and the mental space of its residents.

A particular space of transition manifests itself in one of the large and long barrier-free corridors of the nursing home, with its huge windows that let in a lot of light. Annmarie Adams and Sally Chivers point out that “[w]ayfinding and daylighting” are typical architectural features of institutions such as hospitals and care homes. The aim of this design is to “diffuse generalizations such as ‘old’ and ‘sick’” whereby these buildings “both challenge and reinforce relationships among aging, illness, care isolation, and immobility” (pars. 4 and 5). Adams and Chivers remind us that Polley’s film emphasizes visually what “most of us take for granted: that nearly all long-term care settings include these special provisions” (par. 6).<sup>9</sup> In terms of movement through space, there are two noticeable scenes in the movie. First, we see Grant walking *away* from the camera along the well-lit corridor on his own during his first visit after the required thirty-day settling-in period, devastated that she has not recognized him (00:49:24–00:49:41). Second, Fiona also moves *away* from the film audience’s perspective together with Aubrey, pushing his wheelchair (01:02:15–01:02:38). As a result, the corridor in the care home – the main transitory sphere – serves as a meta-space of transition that forces Fiona and Grant to take on new perspectives and break out in a new direction, which Polley skilfully visualizes on screen. The Meadowlake care home embodies various forms of transformation: from home to “home,” from health to illness, from youth to age, and from loyalty to disloyalty to loyalty; and, in the couple’s final embrace, it also possesses the circular quality of reunion.

The use of light and colours in these and other scenes ties in nicely with the many fades of the film, indicating flashbacks and (the loss of) memories. On the morning of Fiona’s departure from their common home, she is displayed in a close-up of her face, dressed in a white coat, backlit by soft bright light shining in through a window. The lighting, almost resembling a halo, can be read as an allusion to Fiona’s innocence and purity, for she always remained faithful to Grant (00:30:00–00:30:46). It might also point to the metaphorical lights slowly switching off in her mental space as she is about to move to Meadowlake. After she gets seriously involved with Aubrey, her clothes occasionally change to bright colours, which Grant strongly criticizes and calls “tacky.” The use of lighting and colours demonstrates the increasing distance between the couple on a purely visual level. Moreover, it underlines the “transitory nature of the new locale” that Adams and Chivers emphasize (par. 19). In terms of movements through space, Grant generally functions as an intruder in the nursing home

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**9** | *Away from Her* was filmed in Kitchener’s Freeport Health Centre, an award-winning care institution (Adams and Chivers, par. 17).

most of the time. He interrupts Fiona and Aubrey's card game in the common room and also gatecrashes their farewell. Ventura offers a similar reading when she compares Munro's Meadowlake with Lewis Carroll's wonderland: "Like the young Alice, the elderly Grant is an intruder in a territory which is not his and, like her, he meets unmitigated hostility" (178). In the film version, Grant is also a stranger in a place that is figuratively and literally Fiona's new home. As in Munro's story, we witness the events and the (new) impressions of the care home through Grant's critical eyes. In spite of his doubts about the residence, "Munro invites readers to recognize and question the assumptions that may underlie their own perceptions of institutional space" (Jamieson 5; the same can be said of Polley). This is mainly achieved by depicting a happy elderly woman who has found new love in old age – Fiona – in large and bright spaces.

The snowy spaces in *Away from Her* not only link the human psyche with the fading away of shared memories but are also associated with ideas of peace, hope, and rebirth, especially at the end of Polley's film. Here we see Grant and Fiona reunited while the camera circles around them, fading into a grainy close-up of Fiona's younger self before the image dissolves into the snowy landscape with the symmetrical tracks we are familiar with from the film's exposition (01:40:39 – 01:45:15). This sequence recalls an earlier moment in the movie where Fiona and Grant dance together in their living room on the night before they leave for Meadowlake (00:29:35–00:29:56). The couple's last dance in their home is constructed as an intimate and happy rather than a sad and frightening moment, accentuated by the warm lights but also by the audio space of the soundtrack, consisting of Neil Young's song "Harvest Moon," which unites the notions of love, age, and care:

Because I'm still in love with you  
I want to see you dance again  
Because I'm still in love with you  
On this harvest moon.

The characters' movement through space, their dance, and the soundtrack create a couple deeply in love or, more precisely, "still in love" with each other, despite the obstacles they had to face not only during their lengthy marriage but also during Fiona's move to the care institution. These semantics are echoed at the end of the film: in the care home, the camera shoots Grant and Fiona embracing each other in the same position as in the previous dance scene in their living room, taking up the same space on screen. In contrast to the earlier dance sequence, the camera now circles around the two, enhancing the notion of reunion and everlasting love. The film constructs this scene as a loving farewell by reversing the movements through space; whereas Grant and Fiona move in front of a static camera during the dance scene in their country

house, the final sequence operates with a circling camera around a frozen couple in the care institution. As a result, this spatial inversion introduces a shift in perspective, which is manifested on a cinematographic level: both have finally “come over the mountain.” Their relationship has reached an end while the camera moves on. After a fade to the familiar parallel skiing tracks, we see the younger Fiona in a close-up again, turning her head *away* from the spectator, which underscores their farewell. However, the narrative context of the film makes clear that both Fiona and Grant have found new partners, namely Marian and Aubrey. Thus, the circular movements through space as well as the snow imagery equally evoke hope, peace, and a new beginning.

Polley’s adaptation abounds in spatial imagery, oppositions, and metaphors such as houses, homes, care institutions, cars, beds, corridors, and snowy landscapes. Against the backdrop of aging, Alzheimer’s disease, and sanity, Herrera stresses that “Munro clearly questions the ways in which we tend to draw a neat dividing line between sense and non-sense, remembrance and dementia, the world of children and the world of seniors” (120). In the context of adaptation, McGill adds that the film version of the pre-text “bridges the space between an older generation – represented by Munro as well as by Fiona and Grant, ... and the future of the artistic culture ... embodied in young artists such as Polley” (“No Nation” 103). Put simply, and expressed in spatial terms, the film not only crosses the borders between source text and adaptation but also blurs the lines between youth and age, sanity and dementia, and homes and care homes by creating a dialogical atmosphere. In fact, McGill describes the movie as a demonstration of Polley’s “artistic coming of age” as a Canadian artist (109).

We wish to conclude this chapter with some lines from another song that appears during the credits of Polley’s movie. Canadian icon Neil Young’s “Helpless” vividly illustrates the interplay of love and age as well as space and (lost) memory in this Canadian film adaptation:

There is a town in north Ontario,  
 With dream comfort and memory to spare,  
 And in my mind  
 I still need a place to go,  
 All my changes were there.

In this stanza, the words “dream,” “memory,” “mind,” “place,” and “changes” are intertwined in a way that reminds us of the challenges that elderly patients and also relatives have to face when adapting to new situations such as long-term residential care. As we hope our analysis has demonstrated, Alice Munro’s “The Bear Came over the Mountain” and Sarah Polley’s *Away from Her* engage with both the anxieties triggered by conventional stories of dementia and care-home institutions and the possibility of narrating a new story of love, age, and loyalty.



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**Part 4:**  
**Social and Historical Perspectives**



Betsy Struthers

## RISEING FOG

*"I must go in; the fog is rising" – Emily Dickinson*

So often I've driven, been driven down this road,  
I should be used to the nursing home by now.  
But this: push open my mother's door  
to find her slumped, a blue sheet tenting her  
from head to toe. My touch makes her jump,  
she yells, *Give my hallucinations back*, the ones  
the new drug threatens to dispel – Dad has come  
to take her home, her dog snuggles in her lap.

*I used to do so much, I'm just an empty hole,*  
*a smudge.* She thumps the wheelchair's  
arm. Her choice: to scream or weep. She  
claws my stroking hand with yellowed nails.  
The sheet slides off, bares bruises on her shins –  
she's fallen once again. At last, she calms, picks  
at the chocolates I brought her, lets me read  
out loud her book. Drifts in and out of sleep.

I have to leave her there. I have to leave.  
On the bus on the highway home, haunted  
by the vision of her fists clenched tight,  
the look she shot me when I stood to go.  
Focus on the view: an owl hunched  
on a hydro pole, six crows, a kite of geese.  
And over the lake: fog. Over the moraine: fog.  
Over the rattling pane: fog of ragged breath.



# **An Enveloping Shadow?**

## **The Role of the Nursing Home in the Social Imaginary of the Fourth Age**

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*Chris Gilleard and Paul Higgs*

In this chapter we consider the nursing home as both a site and a symbol that fashions the social imaginary of a fourth age. Before exploring the nursing home's dual role, we will first outline the concept of a social imaginary, as well as how the fourth age can be thought of as such a social imaginary. Bearing in mind this conceptual framework, we go on to address some of the ways in which the nursing home plays out its critical role in conferring meanings onto the fourth age, through its organizational culture, its practices of care, and its own representation in the media. The chapter concludes by considering the extent to which the fourth age needs to be acknowledged as a powerful and coherent social representation of much that is feared about later life and how such representations can be challenged within the nursing home, as well as the cautions that need to be exercised when mounting such challenges. This latter point is important in highlighting the tensions that exist in determining what constitutes "good" care under conditions of compromised agency.

## **COLLECTIVE REPRESENTATIONS AND SOCIAL IMAGINARIES**

Durkheim made the case for distinguishing between what he called "collective" and "individual" representations. While the latter he considered to lie within the domain of psychology – the ways in which an individual person makes conscious sense of his or her world – the former exist outside (exterior to) individual consciousness and hence form part of the domain of sociology. The collective understandings of the world are fashioned and reproduced within society, through social processes that pre-date the individual's emerging self, and will continue to be elaborated within the "social thinking" of society long after the individual has gone. Unlike the sectional interests that have been

seen to typify ideology, collective representations serve collective or common interests – creating the kind of shared understandings of society and the social world that enable successive cohorts to become civic and social beings, integrated into and able to sustain the society into which they are born and which will sustain them as necessarily social beings. Collective representations, in effect, enable society to reproduce itself, by representing itself to itself.

While this way of understanding society through its “collective representations” subsequently lost traction in the social sciences, arguably as interest in thinking and writing about social thought as “ideology” grew, renewed interest in this topic emerged with the work of the social philosopher Cornelius Castoriadis (Thompson). It was particularly in his book *The Imaginary Institution of Society* that Castoriadis developed the concepts of the “social imaginary” and “social imaginary institutions” (*Imaginary*). Social imaginaries, he argued, are what give meaning to society and its institutions and in the process help fashion those institutions and help them function as social institutions (*Imaginary* 146). Where Castoriadis’s ideas differed from those of Durkheim was in his belief that social imaginaries were not merely the symbolic representation of a particular social institution or relationship but rather drew upon a multiplicity (or surplus) of meanings, beyond any singular function or signification. This multiplicity of signifiers arises as much from the inherent capacity of human beings to create meanings “ex nihilo” as it does from the range of symbolic functions that an institution or relationship may at any one time possess (*Imaginary* 343–44, 369). Thus terms like *childhood*, *family*, *patriotism*, *justice* or *education* generate multiple images, elicit multiple narratives, and are embedded within multiple practices that may complement or contradict each other. Such social imaginary institutions are both established and undermined by a surplus of signifiers, whose superfluity is underwritten by what Castoriadis called the “radical imaginary,” that power of imagination and meaning making that distinguishes human beings and human society from other, non-human species (“The Psyche and Society Anew” 203). It is this “subterranean ... flow of the radical imaginary” beneath the established social imaginary institutions that ensures the essential plurality of societies and of social representations (“*Philosophy, Politics, Autonomy*” 153).

## THE FOURTH AGE: OLD AGE AS A SOCIAL IMAGINARY

Old age, we suggest, has long functioned as just such a social imaginary – its various sociocultural representations “coexisting, conflictingly” with each other (Castoriadis, “The Psyche and Society Anew” 207). Despite claims for a universal “aversion to age in humans” (Lowenthal 129), there are nevertheless clear differences in the value attached to “old age” at different times and



different places in history (Minois). Medieval images of wise old men with flowing beards bent over their books coexisted with other descriptions of old men whose “shrivelled skin hangs with the hides and flaps with the pelts” (Gilleard 1073). While a similar degree of ambiguity in portraying older men can be observed throughout the pre-modern period (Minois), the portrayal of older women as women has been always less ambiguous and more consistently negative (Minois 229–32). As Maquerelle, in John Marston’s early Jacobean drama *The Malcontent* (1604), complains: for men “[t]he more in years, the more in perfection the[y] grow,” in contrast to women, for whom, once their beauty fades it’s “good night with us” for “[t]here cannot be an uglier thing to see than an old woman” (2.4.57–61).

Rather less emphasis was placed upon the appearance of age during the modern period, as the economies of the state shifted toward paid labour and the ideal was promulgated of the male breadwinner “providing” for the welfare of his or her family (Clark). The progressive institutionalization of the life course that was gradually brought about by the welfare reforms initiated in Bismarck’s Germany in the late nineteenth century and copied throughout Europe and beyond in the early twentieth increasingly segmented the (male) life course into three: a period of childhood, shaped by expectations of education, followed by adulthood, shaped by work, followed by retirement from work and a pensioned old age, shaped by state and/or corporate pension policies (Anderson). More recently, the life course has begun to lose some of this normative structure, with old age ceasing to function as the coherent social category it once was (Gilleard and Higgs, *Contexts*). Changes in the cultural and economic underpinnings of old age have been accompanied by its evident fracturing. Out of the “old” social imaginary of old age has emerged a “new” one, which we have called the social imaginary of the “fourth age” (Gilleard and Higgs, “Aging”; Higgs and Gilleard, *Rethinking*). Though its roots can be traced back to much earlier sociohistorical narratives that distinguished “seniority” from “senility,” a “green” old age from a “decrepit” one, the novelty of the contemporary imaginary has come about from the reimagining of retirement and the emergence of cultural practices and later lifestyles promoting ideals of active, healthy, and/or productive ageing – what we have referred to as the cultures of the third age (Gilleard and Higgs, *Cultures*; “Third”).

## DEMENTIA AS SIGN AND SIGNIFIER OF THE FOURTH AGE’S SOCIAL IMAGINARY

As later life is embraced as a period in one’s life celebrating the “consumerist” virtues of choice, autonomy, self-expression, and pleasure, its realization lies equally in practices designed with one eye on warding off all that might

compromise the exercise of such virtues, namely the shadows and the signs of dependency, incapacity, suffering, and being unable to exercise one's choice or express one's voice (Higgs and Gilleard, *Rethinking*). Integral to this social imaginary are narratives of frailty and abjection, of the loss of status and place, of agency and identity, and of the need to be cared for (Higgs and Gilleard, *Personhood*). Dementia, or Alzheimer's disease, provides a powerfully individualized image of what that means. More perhaps than any other condition affecting people in later life, Alzheimer's has come to symbolize all that is most terrifying about old age and to serve as the dominant discursive frame for the fourth age (Alzheimer's Research Trust, "Poll"; Cantegreil-Kallen and Pin; Cutler; Zeng et al.).

This effect is further accentuated by the research community, and by advocacy organizations such as the Alzheimer's Society that seek to "raise awareness" of the condition in order to expand their role and increase their capture of research funding and charitable giving. Between the press releases of the research community and the reports of the charitable sector, what has been described as an "apocalyptic demography" is constructed that overstates the prevalence of the condition and the impact it has upon wider society. One recent press release, for example, claimed that as many as one in three people would develop Alzheimer's disease at some point, in effect making it as common as such established "killers" as cancer or cardiovascular disease (Alzheimer's Research Trust, "One"). While it is difficult to trace such excessive concerns over developing dementia in later life in pre-modern times (Schäfer), and while the fear of poverty dominated public concerns over agedness in more modern times (Thane 2000), the "Alzheimerization" of aging that became evident in the late twentieth century has seen this condition take pole position in representing the fear of old age in the twenty-first (Adelman).

What makes Alzheimer's so emblematic is the sense that the condition (including both Alzheimer's and related disorders) is not just about rendering people forgetful: it represents a malignant forgetfulness that causes people to lose their sense of who they are and what is most important to their sense of self, in effect to lose their grip on, and their place in, the world. It progressively weakens people's connections to society and their access to and use of its "collective representations," as well as their connections to themselves and their "individual representations" of their personal past. While clinical researchers have sought to qualify the nature and extent of such losses, recognizing the large variability among people experiencing these conditions, such empirically based caution seems to have had little public impact. Although media representations of Alzheimer's/dementia have increased greatly since first emerging in the 1980s (Kang et al. 691) they have remained mostly negative, displaying what Peel has called "a largely absent moral economy of hope" regarding those suffering from this condition (897). Almost universally, such representations

emphasize “the catastrophic nature of dementia” and “the horror of the condition” (Peel 890). News of “breakthroughs” in research represent perhaps the only example of a significant “counter-framing” discourse, but these stories must be set against the large number of negative frames that have been adopted, representing dementia as “confiscating a person’s spirit,” appearing like “a thief who steals a person’s life,” “synonymous with being condemned to death” something that can cross the path of any ageing person simply by virtue of their age, while auguring a return to childhood and childishness (van Gorp and Vercruyse).

Given such media coverage, it is hardly surprising that much of what is nowadays considered most fearful about old age is this prospect of developing Alzheimer’s/dementia. While old age once threatened – and frequently realised – a loss of power and status, whether framed in terms of declining physical attractiveness or prowess or in terms of reduced earning power, such losses pale into insignificance when set against the widespread fear of losing not just one’s status but also one’s mind. For most of the nineteenth and much of the first half of the twentieth century, for most people, old age was a time of poverty (Thane). The image of the nineteenth-century alms-house (in the United States) and the workhouse (in Europe) symbolized that threat; once entered, these institutions were hard to escape from. However, after their introduction, old-age pensions served as a lifeline for the “aged and impotent,” ensuring that most could now avoid this fate. During the period of the postwar welfare state, the majority of these institutions of impoverishment were replaced, in many cases by more sociable, less intimidating residential-care homes or by long-stay hostels or hospitals where significant numbers of the more infirm older people ended their lives. While some combination of infirmity, limited income, and a serious lack of social capital (in the sense of weak or absent family networks) still served as the immediate cause of older people’s “institutionalization,” the majority of ill, infirm, and poor pensioners managed to remain at home, their suffering invisible to the health and welfare services and the wider public alike (Williams et al.; Williamson et al.). Dementia, though evidently present, was just a part of that greater silence, that marginalization of age and infirmity which, when discovered, led primarily to calls from researchers in the field for the state to expand its health and welfare services in and to the community rather than turning back to the earlier solution of building more institutions.

Following the first “crisis” of the postwar welfare state, during the 1970s, there was some expansion of “community care,” in the sense of an expansion of health and welfare services provided to people living at home. At the same time, the emergence of the “cholinergic hypothesis” research paradigm saw “senile dementia” upgraded, first becoming “Senile Dementia of the Alzheimer’s Type” (SDAT; see, e.g., Reisberg et al., Summers et al.) and then quickly being rebranded as “Alzheimer’s disease and related disorders” (ADRD; see,

e.g., Eagger et al.). A stirring of public interest in the problem of dementia became discernible as a new discourse emerged framing dementia as a public health problem – a “rising tide” that sooner or later would need to be addressed (Arie and Jolley; Health Advisory Service). Subsequently, funding began for research into the problem of “caregiver burden,” effectively extending interest in dementia as a problem not just for individual older people but also for their families, including their adult, working-age children. By the mid-1980s, novel drug trials were being initiated of various potential “anti-dementia” medications (Chatellier and Lacomblez; Eagger et al.; Summers et al.). Since these invariably enlisted the support of carers to complement the clinician’s assessments, with ratings based on the person’s “behavioural functioning” or general “dependency,” these two developments proceeded with a kind of synergy, as carers’ and researchers’ reports of dramatic improvements in patients’ mental functioning began making headline news (see, e.g., Nelson; “Drug”; “New”).

The combination of disease-modifying treatments, new “intermediate,” semi-institutional settings for care, and enhanced “community-care management” were trialled with the hope that some combination of care and treatment might “prevent” institutionalization. By the time the twentieth century was reaching its end, the prospect of drugs to treat dementia, community-care services to keep people with dementia at home, and a range of “psychosocial” interventions that promised to preserve the personhood of people with dementia (Bourgeois et al.; Mittelman et al.) had the cumulative effect of making institutionalization – that is, entry into a nursing home or other residential care – even more a mark of failure than it had been before. Set against these bright lights of hope, the shadows in the background were darkening.

## **THE NURSING HOME AS SIGN AND SIGNIFIER OF THE FOURTH AGE’S SOCIAL IMAGINARY**

This optimism was retained for a short time into the twenty-first century. It was soon becoming clear that these solutions were nowhere near as credible as they had once seemed. Day care and respite services were cut back, anti-dementia drug trials petered out, and psychosocial interventions were increasingly targeted toward people who were not “aging in place” but dementing in nursing homes (AD 2000 Collaborative Group; Cabrera et al.; Cooper et al.; Schneider et al.). Trends in long-term care (LTC), in developed economies at least, indicated that community services were being increasingly stretched to meet the needs of older people to age in place. As the threshold for receiving help rose, nursing homes were having to deal with a growing intensity of need among their residents (Meijer et al.; Gori et al.; Ranci and Pavolini). Confusion, incontinence, and immobility exemplified the chronic conditions affecting an

increasing majority of nursing-home residents, as the nursing home became the endpoint when the drugs had failed, the day centres were no longer able to support the families, and no other sources of respite were left beyond that of the institution (van den Brink et al.).

In the new millennium, dementia and the nursing home have become indissoluble entities, the latter the institutional location where the former reaches its ultimate form. They serve as the collective representation of the fourth age, signifiers of the failure to age well, to age mindfully, and to sustain the practices of self-care. Within the nursing home, the daily round can seem a continual challenge to hold at bay, for as long and as much as possible, the ultimate abjections of the fourth age. It is a challenge not confined to maintaining what has been called the “personhood” of the residents suffering from dementia and related disorders; it is equally a challenge for staff to maintain their own personhood in the face of constant threats to their own moral identity as carers. Care workers who face the daily task of doing the dirty work of care must do so without succumbing to its potentially contaminating influences – contaminating their bodies, their feelings, and their sensibilities (Sandvoll et al.). It is this dual process of resisting the penetration of the social imaginary of the fourth age into the lives and experiences of those who live and those who work in the nursing home that is addressed in the final section of this chapter.

## **RESISTANCE AND RESIGNATION IN THE FACE OF THE FOURTH AGE**

In the twenty-first century, developing dementia is one of the most powerful predictors of who will and who will not enter a nursing home (Houttekier et al.; Luppá et al.). It is also one of the few conditions that would induce the majority of adults to at least contemplate moving in future into a nursing home (Werner and Segel-Karpas). The nursing home, more than any other social institution, realizes the social imaginary of the fourth age within contemporary society. As with dementia, “the popular press focuses on nursing homes as contemporary ‘gulags,’ sites of increasing use of chemical restraints, places of abuse and violence, and locations of tragedies that reveal high levels of neglect” (Chivers 134–35), casting what Gubrium and Holstein have termed “an interpretive shadow on meaning” over the frail bodies and failing minds of its residents (521). Yet nursing homes remain on the periphery of society’s vision, as much as the alms-house or the workhouse were over a century ago. They are brought into the public gaze, it seems, only when a scandal breaks out or a company collapses (Lloyd et al.). Although nursing homes are a real presence in the lives of many more people than just the staff and the residents (because of the involvement of families – both as occasional or regular visitors, and as proxy clients looking into the acceptability of a home for their relative, partner or

friend), the public's experience and understanding of the nursing home seem to arise more from media news stories portraying these institutions in a frankly negative or less often neutral light (Miller et al.).

It is a curious paradox that while abuse, indignity, and scandal provide the main focus of media attention on the nursing home, these darker aspects of care feature least prominently in what could be called the "professional literature on care work." Ever since Everett Hughes introduced the term "dirty work" to refer to the degrading, undignified or immoral aspects of work performed by various occupational groups, it has become common to refer to certain occupations, including that of the nursing-home care worker, as pervasively dirty, because of workers' continual contact with physical, moral, or socially tainted "dirt" (Ashforth and Kreiner, "How"; "Dirty"). What helps define dirty work is its capacity to taint – and hence to marginalize and render abject those who perform such tasks. Given these threats to dirty workers' self-regard, it has been argued that in response there is a greater likelihood that "a strong occupational or workgroup culture will emerge to counter that threat" (Ashforth and Kreiner, "How" 431). One consequence is that the more troubling aspects of the work tend to be excluded from discussion, and instead the work is reframed as a "morally valuable" service, recalibrated as "a necessity shield" or retold through "rites of initiation" as a marker of emotional moral or physical strength (Ashforth and Kreiner, "Dirty").

In the process, the hurt, indignity, and suffering of both residents and workers may be minimized and the emotional damage denied, repressed, or reattributed to the residents' neglect by their families. Tensions between staff and family are not uncommon, as the guilt experienced by family members who feel they have failed to look after their relative long enough or well enough is displaced onto the perceived failings of the staff in carrying out their duties, who in turn resent the (c)overt hostility of relatives (Bauer). Complaints may arise that staff neglect residents (such as losing items of their relatives' clothing), that they do not give residents enough time (to eat, to get dressed or to find their way to the toilet), or that they are inattentive to their needs (responding slowly or not at all to calls for help, or failing to prevent episodes of incontinence). In turn, staff may feel simmering resentment toward these criticisms, secretly harbouring the belief that the relatives are the ones who have failed or "given up" too easily on their dependent while having little understanding of the pressure that they, the staff, are under looking after so many mentally and physically frail residents (Abrahamson et al.).

Thus the abjection and the failure that shape the social imaginary of the fourth age within the nursing home envelop not just the residents but relatives and staff as well, leaving each group of stakeholders depressed, demoralized, and dissatisfied. The moral imperative to care that is shared by all concerned is continually confronted by residents who often do not wish to be cared for –

whether because they are angered or agitated by the unwanted intrusion it involves, or because they fail to recognize the identity or intentions of those doing the caring (Hoeffer et al.). It is one thing to help those who either recognize their helplessness (such as people with severe physical disabilities) or whose have no prior experience of autonomy or independence (such as infants or people with developmental disabilities), where the moral imperative of caregiving is realized through mutuality and (asymmetric) reciprocity; it is another when neither mutuality nor reciprocity can be realized. While it would be a gross exaggeration to confine examples of the latter to people with dementia, it is still the case that most examples of “conflicted caregiving” are linked to this condition, making care of older people with dementia the setting for further abjection and ignominy (Higgs and Gilleard, “Frailty”).

## CARE AND ITS UNINTENDED CONSEQUENCES

It would be misrepresenting the nursing home if it were seen as little other than a site of mutual abjection, and it would be misrepresenting nursing-home staff if they were seen as engaging in little more than reframing their experience and practices in ways to safeguard their self-esteem in the face of doing a dirty and demoralizing job. There are many examples of staff and residents forming open, caring relationships characterized by mutual feelings of attachment (Costigan; Wilson et al.). For many staff, the dominant frame for their work is that of “family” (Dodson and Zincavage). But even when care is given within such a framework, there exists the possibility that caregiving itself undermines the autonomy and compromises the identity of the resident, while staff who are less engaged with the residents may paradoxically strengthen the collective agency of the residents by causing them to come to each other’s aid (Ryvicker). These and many other contradictions of care are embedded within the organizational culture of the nursing home. Work done to resist the prospect of a social death and protect residents against the shadows of a fourth age may risk demanding too much or alternatively infantilizing them (Gilleard and Higgs, “Social”). A too intense focus on delivering comprehensive physical care may minimise the indignities of pain and suffering, while quietly nursing residents into a kind of social death. Offers of aid and assistance to keep residents “dignified” (like bathing, showering, and toileting) may elicit only aggression as such aid is perceived as intrusive, unwanted, and threatening to an already vulnerable person (Gates et al.).

The nursing home itself produces multiple meanings by which both staff and residents can be represented. It may be represented through a number of different frames, ranging from a “home from home” to a biomedical “skilled nursing” facility through to a necessary institution to prevent the abjection of

extreme agedness from leaking into the public sphere (Nakrem). Foucauldian narratives can be employed to represent the nursing home as part of modern-day “bio-politics,” controlling the unruly bodies of the uncivilized old (Hyde et al.), but such seemingly radical perspectives leave unaddressed what most families want for their frail, aged relatives: a safe and dignified life as free from suffering as possible. Creating a setting where that is possible necessarily sets in motion practices and procedures that involve an asymmetrical set of relationships between carers and those being cared for. This asymmetry is a function of both relational and representational power, operating at the level of what Foucault has called the agonisms of freedom, as much as through systems of governance. What this amounts to is staff who both are more able to look after the residents than the residents themselves and also have more power to represent and enact the “reality of care” than do the residents (more so in those “units” where most residents suffer from dementia and related mental infirmities). While it could be argued that the nursing home itself – the institutional matrix determined by the commissioning authority and the provider organization – operates its own separate systems of power, through its regimes of corporate governance, regulating the conduct of staff and residents alike, this overarching regulatory structure may add to, as much as it ensures against, enveloping the residents within the shadows of a fourth-age imaginary.

Paradoxes of care abound within the interstices of power that permeate the nursing home. Since the residents mostly lack power to resist the institutional systems of governance of the nursing home (and arguably have entered the nursing home precisely for that reason), their agency is likely to be exercised more in the daily agonisms of freedom that constitute the interactions between staff and residents, and between the residents themselves. While the former are marked by the asymmetry of power noted above, the latter are least affected by such asymmetries. Does that mean that here at least, in resident-to-resident interactions, lie the best chances for sustaining one’s agency, representing one’s identity, and establishing one’s place in the social world? Perhaps not. Perhaps such possibilities become less realizable because most residents have lost their power to form, maintain, and adapt their social relationships to others, especially others who share the same weakness. While the aged poor in the Victorian workhouses were able to and did write letters of complaint about the conditions in the wards or the infirmary, few residents of today’s nursing homes have the means to do so – not because of poverty, not because of a lack of education, not even because of a lack of social capital, but because of their own mental infirmity: their inability to represent themselves in and to the social.



## CONCLUSIONS

The nursing home has long been portrayed in a negative light, as an oppressive institution, prone to scandalous practices and serving as an antechamber to the grave. As the residents of these institutions have become more prone to physical and mental infirmity, and as the care offered by these institutions has intensified, the power of staff and residents has consequently become weaker in resisting these institutions' "interpretive power" to confer upon old age the imaginary of a fourth age. The direct experience of life within the nursing home remains confined to a small group of people: the residents, who are increasingly mentally and physically frail, and the staff, who are increasingly drawn from the poorer and more marginal groups within the workforce. Consequently, the nursing home's collective representation relies heavily upon reports in the media. Since media attention is strongly influenced by issues of newsworthiness, it is hardly surprising that abuse, scandal, and poor standards of care dominate the framing of the nursing home. It is in this sense that we have argued in this chapter that the nursing home acts as a potent signifier of the fourth age and what it represents: society's greatest fears of old age.

Resistance to that imaginary is difficult to mount and even more difficult to sustain, not least because it is mediated through the frames of the news media, rather than constrained within the everyday practices of the staff or its visitors. Further, the densification of disability that has taken place over the last two decades means that the residents are less and less able to position themselves as dissatisfied customers or discontented citizens – in the way that the aged residents of the old workhouses or alms-houses once were. Who can provide the "counter-frames" against such representations, and how? Arguably, the research community, rather than serving such a function, only adds to it by critiquing standards of care, particularly by identifying care practices as contributing to, rather than preventing, a malignant social psychology that makes the residents more demented than they would otherwise be. While such critiques are no doubt motivated by the desire to "do something," to improve the quality of life of the residents – in short to defend them from being engulfed by the shadows of the fourth age – the evidence of their success in so doing remains limited at the very least (Beerens et al.; Olsen et al.).

Caught by what we have called "the moral imperative of care" (Higgs and Gilleard, *Personhood*), it can seem that staff working in the care sector are assailed on all sides by a morally ambiguous task, namely to treat the people they care for in ways that depend upon a narrative that their daily experience either confounds or frankly contradicts. Work that is carried out itself under a shadow – the shadow of "dirty work" – requires care workers to manage their own feelings of disgust and indignity while maintaining a semblance of their own and their residents' sense of worth and dignity. The general lack of signs

of moral worth assigned to their work and to their place of work (demonstrated, in pre-modern times, by the religious nature of their calling and their place of work) goes back to the poor laws. While early-twentieth-century reforms saw hospitals and hospital nursing rise in standing as nursing became professionalized and increasingly allied with medicine, the workhouses and alms-houses – and now nursing homes – are staffed predominantly by non-professionalized hourly-paid labour: the legacy of the pauper nurse and the workhouse maid.

To achieve change, to strengthen the capacity of staff and residents to resist the shadows of the fourth age, requires more resources to combat the devaluing of the work, the marginalization of the workplace, and the spectacular nature of the care environment, where visitors are encouraged as much as to observe as to share in the quality of care. More specific responses can be suggested, from the creation of university-affiliated nursing homes to the development of shared citizenship in the running and shared ownership in the management of the nursing home itself, with government or local-authority incentivization of such collective systems by staff, relatives, and those residents most able and willing to contribute. Achieving any kind of cultural change in nursing homes is difficult (Shier et al.). The Green House model<sup>1</sup> represents a definite step toward implementing this agenda, for example, although even this has proved difficult to implement consistently (Zimmerman et al.). So long as the nursing home remains both a symbol and a structure that realizes the social imaginary of the fourth age, it will continue to be the site where the struggle to resist that imaginary is most acute and most challenging. Rather than hiding from the uncomfortable contradictions of later life by segregating a space for the fourth age within the nursing home, the opening out of this struggle is important, even if – or most likely because – its resolution is so hard to realize.

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1 | For a description of Bill Thomas's Eden-Greenhouse model, see Brune.

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# **A New Home, A New Beginning, A New Identity**

Old Age, Life Narrative and Self-Presentation in the Novel

*The Real Captain's Sea* by Zvonko Todorovski

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*Marija Geiger Zeman, Zdenko Zeman, and Mirela Holy*

## **A PLACE FOR NEW BEGINNINGS: PHYSICAL ASPECTS AND SOCIOCULTURAL MEANINGS OF HOMES FOR OLDER AND INFIRM PERSONS**

In the article “The Retirement Home, Alive with Intrigue,” written on the occasion of the publication of Jill McCorkle’s novel *Life After Life* (2013), Paula Span notes that in recent years the topic of aging has become more visible in popular culture, with “senior communities, nursing homes and assisted living facilities playing a variety of roles.” Since the middle of the last century, the organization of seniors’ and nursing homes, as well as the daily lives of their residents and employees, has become the subject of numerous influential anthropological and sociological studies. Some of these studies have revealed extremely poor living conditions in these institutions (Gubrium xiv; see Zeman and Geiger Zeman 74). Research based on ethnography and qualitative methodology often refers to the well-known concept of “total institutions” developed by Erving Goffman. The interpretative paradigm developed by Berger and Luckmann and inspired by symbolic interactionism is very useful for our analysis, as is the “dramaturgical” approach of Goffman himself. These authors inspired anthropologist Rene Somera, who in the 1980s carried out ethnographic research in a Philippine “home for the aged, an institution designed for elderly living” (1). We fully accept Somera’s statement that this kind of institution is a physical and social space that can be analyzed in terms of geographical, physical, and social categories (Somera 9; see Zeman and Geiger Zeman 74, 75). A home for older and infirm persons is an extremely interesting, multi-coded institution that is always located in a real, physical, and geographical locality, yet it has a complex, multilayered meaning for those who live in it as well as for their families, for its employees, and for society at large. Stephen Katz argues

that the “nursing home” is “a micro-complex of architectural, administrative, financial, clinical, familial, symbolic, and emotional interactions and power relations” (204).

The plot of the 2008 novel *The Real Captain's Sea* (*More pravog kapetana*) by Croatian writer Zvonko Todorovski (1960–2010) centres on a home (hereafter “the Home”) for older and infirm persons in Varaždin (see Somera 1997),<sup>1</sup> a medium-sized town in northwestern Croatia.<sup>2</sup> From his description of the Home, it is evident that Todorovski was very familiar with public institutions for older people in Croatia, and especially with their architectural design, interior design, and spatial layout – that is, with their “physical setting” (Somera 61). The interior of the Home suggests pleasant, almost hotel-like accommodation: a spacious lobby with a reception desk, a large “horseshoe-shaped” bar and “club seating,” a “glazed lounge” reminiscent of a conservatory, a smaller room with an outdated TV and comfortable armchairs, and a pleasant restaurant dominated by warm colors and serving delicious food (even catering for the nutritional preferences of the guests; there are, for example, dishes for diabetics and vegetarians) (Todorovski 18, 20, 29).<sup>3</sup> A corridor to the left of the entrance leads to the office units, while the upper floors house both single and double rooms for residents, which can be reached by an elevator or stairs. There is a small kitchen on each floor where residents can prepare hot drinks and meals (Todorovski 29). It is important to note that residents can arrange their rooms according to their wishes. Thus, for example, the room occupied by the male protagonist, Franko Perić, is lined by bookshelves and so resembles a library (Todorovski 46). In addition, each room has a balcony where residents can grow flowers, and they can also enjoy the lawn and trees behind the building (Todorovski 29, 45).

The overwhelmingly pleasant interior design convincingly refutes the widespread belief (held by Franko himself) that homes for older and infirm

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**1** | Institutions specialized in the provision of care to older and disabled people in Croatia are called “homes for older and infirm persons.” These institutions provide half-day and full-day care services and also offer help or care to older persons at their private homes (Šostar and Fortuna 40; translated by Barbara Katić). In the case of full-day care, residents receive complete services that include permanent “accommodation, food, personal hygiene maintenance, health care,” organized work activities and opportunities for the active “use of free time” (40). Almost every such institution accommodates older persons in a residential area (similar to a hotel) and runs an intensive care unit that resembles a hospital facility. The story in the novel analyzed here takes place in the residential area of the home for older and infirm persons.

**2** | We are grateful to our friend and colleague Jadranka Pintarić for her recommendation that we read this book.

**3** | Parts of the novel *The Real Captain's Sea* (*More pravog kapetana*) by Zvonko Todorovski cited in the article are translated by Barbara Katić.

persons are “dark,” desolate, and sad places (Todorovski 19). In Croatia, where such institutions are frequently equated with public housing for the poor, a very gloomy image of homes for senior citizens has dominated for a long time (Geiger Zeman et al.). The family is traditionally regarded as the primary care provider for its older members, and moving to a home for older and infirm persons was considered a disgrace for both the older person involved and for his or her family members, especially the children. However, social, economic, and cultural changes as well as changes in relationships within the family have gradually led to shifts in perceptions and attitudes toward homes for older and infirm persons. Today, more and more older people decide to move into an institution of this type (Geiger Zeman et al.), resulting in excessive demand, especially in the larger cities where accommodation facilities are insufficient. For this reason, in the capital of Zagreb, ten-year waiting periods for single or double rooms in certain institutions are not unusual (Geiger Zeman et al.; Žganec et al. 182). In *The Real Captain's Sea*, both Franko (whose sister Lucija helped him obtain the accommodation in Varaždin) and Slavica Pavletić, Franko's friend and the female protagonist, face this problem.

In this context, the question about the relationship between society/social reality and art, specifically literary work, arises. From the position of the “reflection approach,” art (“fine,” popular, folk, etc.) “contains information about society” or “tells us something about society” (Alexander 21). On the other side, the “shaping approach” or “shaping theories” are based on the idea that “art can somehow put ideas into people's heads” or that “art has an impact on society” (Alexander 41). Both approaches show that links between society and art (or a specific literary work) are not linear and simple but multilayered, complex, and dialectical (Alexander 33). Any work of art (novel, film, painting, music video, etc.), as a “cultural product” (or cultural text), “reflects and shapes the social world in which we live” (Sutherland and Feltey vii). Sociological reading/watching of literary or cinematic fiction includes detecting, identifying, and analyzing “social experiences, institutions, and the theoretical perspectives within them” (Sutherland and Feltey xi). This argument is in perfect harmony with the statement of the famous American sociologist Lewis A. Coser, as presented in the book *Sociology through Literature* (1972):<sup>4</sup>

Nothing human ought to be alien to the social scientist; if a novel, a play or a poem is a personal and direct impression of social life, the sociologist should respond to it with the same openness and willingness to learn that he displays when he interviews a respondent, observes a community, or classifies and analyzes survey data. (xvi)

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4 | About dialogue between sociology and literature, see Geiger Zeman and Zeman 227, 228.

In this chapter, we turn to a novel that offers “a personal and direct impression” of an extremely important aspect of contemporary social life that we have studied in homes for older and infirm persons in Croatia using qualitative methods (in-depth interviews, participant observations, focus groups, etc.). In *The Real Captain's Sea*, Todorovski skilfully combines elements of fiction with descriptions of the specific social, cultural, and economic contexts in which older people live in Croatia, organize their lives, and spend old age in institutional settings. This novel is thus very useful for reading through a sociological lens.

The basic prerequisite for the successful adaptation of older persons to a new and institutional environment is their autonomy to make decisions and their free will to move to a home for older and infirm persons (Geiger Zeman et al.). In the novel, Franko and Slavica, like their friends Professor Bučić and Doctor Lipovac, come to the Home in Varaždin voluntarily. Although readers do not learn about the factors that motivated Bučić and Lipovac, it is evident that Franko and Slavica each had different reasons for moving to the home.

The main reasons behind Slavica's arrival at the Home were intergenerational misunderstandings and disharmonious relationships within her immediate family. Unlike Franko, who has no children, Slavica is the mother of two adult married sons, Dalibor and Vladimir, who take care of her “as much as they can” and help her financially (Todorovski 74). However, she does not consider living together with them and their families to be a viable long-term option (Todorovski 74). Until now, Slavica has spent her life in Vinkovci, a small town in eastern Croatia. As her house was devastated during the Homeland War (1991–95), she lived with her son Dalibor for some time. The situation was bearable while her grandchildren were small and she was taking care of them, but as they grew older she began to feel that she was a burden in the small apartment where they all lived, and the relationship with Dalibor's wife was far from harmonious (Todorovski 75). She then went to stay with Vladimir, but since the situation there was even worse, she decided to move to a home for older and infirm persons until her house was rebuilt. Due to very long waiting times for a place in a home for older persons in the nearby town of Osijek, she came to Varaždin, where she was able to obtain a single room after only two months (Todorovski 75). Her new home accommodates people whose “children do not want to live with [them] anymore” as well as those left alone (Todorovski 57). The novel does not discuss the reasons behind people's arrival at the Home; the important thing is that the novel's characters are fully aware of the fact that some of the Home's residents have good pensions or are financially supported by children and/or grandchildren (Todorovski 19, 20), allowing them to stay in this institution and easing their lives there.

Chronological age as a dividing line between youth and old age is reflected in the spatial settings of the novel: some of the locations are determined by

the age structure of their permanent and occasional users and visitors. For example, the café in the center of town is described as a space dominated by young people, while the Home appears as its opposite. It is an institution, a place intended for people aged over 65; Todorovski describes it as a kind of “island” that is actually “only a seemingly isolated place because it could be reached as well as any other place in town whenever one wished” (45). However, the Home is a segregated locality where older people are separated from the younger and where the physical accessibility of the residents does not annul a certain existential discontinuity between them and the rest of the world (Stone 63). As an institution determined primarily by the age of its residents, the home for older and infirm persons produces common images that reflect different age stereotypes; this is evident even in the official name of such institutions. As mentioned above, in Croatia this type of institution is officially called a “home for older and infirm persons.” The name implies that old age and infirmity – and in Slavica’s opinion, also solitude – are “the core of powerlessness” (Todorovski 21). They are inextricably linked and mutually conditioned. The noun *infirmity* is often defined as a mental or physical failing or weakness, and it is frequently erroneously associated with older age alone.<sup>5</sup> Therefore, the very name of the institution permanently confirms this stereotype and the unfounded “commonsense” belief of the mutual conditionality of old age and disability (Stone 62, 63).

If we focus on the social aspects of everyday life in the home for older and infirm persons, it is evident that many people are involved – from residents to employees and visitors (for example, family, volunteers, students, and so on) (Somera 74). Todorovski deals mainly with the relationships and social interaction of the residents, primarily Franko and Slavica, giving only fleeting and partial information about the other types of relationships inside the Home, but even these few episodes provide a deeper insight into the network of social relations within this micro-social universe. As in every institution, the people interacting there are of different backgrounds and have diverse experiences and lifestyles, while their relationships and daily lives are guided by certain formal rules laid down by the Home. However, it is clear that some of these rules are not consistently enforced; indeed, their non-compliance is tacitly tolerated (for example, although smoking is prohibited, some residents still smoke) (Todorovski 105). Another important aspect of life in the Home is routine (Geiger Zeman et al). In fact, as Berger and Luckmann observe, “all human activity is subject to habitualization” (70), since activities that we frequently repeat form patterns that can be reproduced with little effort, liberating us from the burden of choice and thus bringing psychological relief (70, 71). It is important to point out that routine and the predictability of life in the Home, as

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5 | “Infirmity.” *Vocabulary.com*, <https://www.vocabulary.com/dictionary/infirmity>.

is emphasized by Todorovski, should not be understood as the performance of actions that have lost sense for the individual. As Berger and Luckmann clarify, “habitualized actions” have meaning for individuals, yet their significance is not constantly redefined anew but is rather “taken for granted” (71). Todorovski points out that along with the formal, externally imposed rules of the Home, life there is also managed by old age as the supreme master whose laws and regulations the residents must obey (73). Age and youth, past and present, are themes that pervade Franko’s and Slavica’s everyday conversations and lead us into the social subworlds and friendship networks that exist within the social reality of the Home, also revealing an intriguing aspect of their interpersonal relationship.

## **PAST AND PRESENT AS YOUTH AND OLD AGE**

In their daily communication and life narratives, Franko and Slavica discuss, among other things, universal human themes, the past and present, old age and youth, truth and lies, authentic and inauthentic life, and friendship. The novel is interesting primarily because it reflects these important philosophical (for example, transience of life), anthropological (for example, identity issues and the narrative dimension of identity), sociological (for example, the organization of institutional care for older persons, friendship, and social relations within an institutional context), and gerontological (for example daily routines of older persons) topics, demonstrating their deeprootedness in the context of personal biographies and the broader sociocultural framework in which the protagonists are embedded.

These themes of youth, old age, and the transience of life are present in Slavica’s and Franko’s recollections of people in the past as well as in their interpretations based on idealized images of youth. This indicates two important things: first, youth and old age are constructed categories imbued with different meanings, and second, individual interpretations of youth and old age are rooted in everyday and commonsense knowledge, which often implies and supports age-related stereotypes and reductive collective narratives. This helps to maintain “the binary opposition of ‘young’ and ‘old’” (Kribernegg and Maierhofer, “Ages” 9). Slavica’s perception of old age is not static. At first, she is predominantly negative and pessimistic, caught in a narrative of “loss” (Baars 106, 107) and “human decline” (Wangler 114) rooted in her personal biography and the lived experience of sacrifice, loss, personal unfulfillment, and dissatisfaction with both her current and her previous life. From her contemporary viewpoint, the past was pleasant and good, though it did not seem so at the time. Resigned and disappointed, she no longer wants or expects anything from life. She believes that old age is “a time when there is no more present”

(Todorovski 21) and when the only things left are memories of the “good old days.”

Franko’s position and his interpretation of old age are more complex and ambivalent because they are composed of elements that suggest an understanding of “aging as a dialectic of loss and gain” (Baars 106). To Franko, old age is a time for a “new beginning” (Wangler 115) or “a positive opportunity to embark on a new life” (Grebe et al. 89). Released from numerous restrictions and previous responsibilities, he now has the opportunity to occupy himself with self-realization and the realization of many of his previous aspirations. He responds to Slavica’s (age) pessimism with a positive image of “old age as superiority” (Wangler 115), that is, a time marked by maturity and wisdom (Todorovski 21). On another occasion, Franko, in conversation with Doctor Lipovac (after it is revealed that Professor Bučić actually holds a PhD in physics), defines old age as a period in which interests and priorities are changing (for example, titles and status are no longer so important) (Todorovski 64). Nevertheless, though he would no longer want to be a young man of 20, a story about events lived in the past is a reminder of youth, good times, and “the good old days”: “Youth is a damn beast. And what is worst, the older you get, the more beautiful it seems” (Todorovski 54). Alongside youth and old age, the important reference points around which the story develops are the complementary coordinates of past and present. For Franko, his change of residence opens the opportunity to view his past from the present position of his older years.

## THE BRIEF HISTORY OF A FRIENDSHIP

Friends occupy an important place in the lives of people of different ages. Specific forms of interpersonal relations have different meanings for individuals, and in academic literature, there are various definitions and diverse approaches to the study of social relationships of this type. Precisely these insights suggest that the category of friendship is very wide and flexible. Scholars distinguish between different types of friendship, for example, “simple friendship” (“associate, useful contact, favour friend, fun friend”) and “complex friendship” (“helpmate, comforter, confidant, soulmate”) (Spencer and Pahl 60). According to Graham Allan, “normative definitions of friendship” highlight some of the crucial features of this relationship: egalitarianism, reciprocity, and symmetry (qtd. in Policarpo 174). Thus friendship is determined primarily as “person-oriented” and bringing “intimacy and enjoyment” to all parties involved (Policarpo 173). In the broadest sense, friendship pertains to informal relationships between people who visit each other, spend time together, discuss (usually personal) issues important to them, consult or support each other mutually or even materially (Claude S. Fischer, qtd. in Policarpo 172; Spencer and Pahl 59).

In a narrow sense, friendship involves “closeness and intimacy” (Malcolm R. Parks and Kory H. Floyd, qtd. in Policarpo 172). Of course, these two qualities of friendship are complex. “Closeness” covers a wide range of “emotional, cognitive” and even physical intimacy (Policarpo 172), while “intimacy” involves “self-disclosure, emotional expressiveness, unconditional support, physical contact, trust, (sharing) activities and sexual contact” (Michael Monsour, qtd. in Policarpo 172). Real friendship relations, of course, deviate from this somewhat idealized definition. Liz Spencer and Ray Pahl define friendship as a kind of “personal community” with different forms (32) and functions for the people involved. In their study, they offer an answer to the seemingly simple question, “What is a friend?,” establishing that friendship is a relationship with a specific quality: it is chosen between persons “who have something in common” (for example, “the same sense of humour or similar interests,” place of residence, lifestyle, etc.); these individuals “enjoy each other’s company,” visit each other, go out, communicate directly or indirectly (by mobile phone, telephone, email, social networks, etc.) or perform certain activities together (for example, exercising, walking, painting, learning foreign languages); they give each other practical and “emotional support,” feel comfortable together, confide in each other, and feel a mutual obligation to one another (Spencer and Pahl 34, 59).

Like life itself, friendship is not a static form. It is, rather, a procedural, fluid, and changing relationship. In this respect, Spencer and Pahl talk about “friendship career” or the “history of friendship, that ... can follow a number of different” and unpredictable “trajectories” (72). Franko and Slavica’s friendly relationship undoubtedly falls into the category of “complex friendship” (Spencer and Pahl 60) and can be traced through three basic stages: the establishment, termination, and restoration of the relationship.

Friends are “chosen because of the need to reflect our own image in the other. Friends are perfect mirrors of ourselves” (Todorovski 57). Slavica and Franko’s friendship commences with Franko’s arrival at the Home and their encounter at lunch in the Home’s restaurant. Their friendship is triggered by a very simple fact: Slavica is thrilled by the sea, although she has never seen it, while Franko comes from Split – a town on the Adriatic coast – and introduces himself as a retired sea captain (Todorovski 25). In this way, “one side could easily give what it had in abundance, something the other side was so painfully lacking” (Todorovski 27). Slavica, when she first sets eyes on Franko, imagines that he has spent his working life as a bank director or senior bank official (Todorovski 34). The fact that friendship indeeds plays an important role in the lives of older persons is underlined by the effect of this friendship on Slavica who, before Franko’s arrival, spent her days in the Home in predictable monotony. During this time, she did not establish a close relationship with any resident. Her contacts amounted to polite greetings, participation in organized parties (at which she pretended she was having a good time), and reading, “the



only true entertainment” (Todorovski 20). It is precisely the arrival of Captain Franko that transforms Slavica from someone locked in a constant struggle with her memories into an enthusiastic and cheerful person. Her friendship with Captain Franko and his stories of ships and distant voyages allow her to compensate for the frustration caused by her being unable to realize her lifelong dreams: to visit the coast, enjoy the sea, and travel to distant countries. She believes that through her meetings with Captain Franko she will accomplish all that she has ever dreamed of (Todorovski 30). Moreover, sometimes while listening to his adventures she feels a “friendly envy” because she would like to have similar stories to tell (Todorovski 41). However, the friendship is based on the fact that Captain Franko is her opposite: “His experience transcended the majority of the books she had read. She admired the wisdom derived from real life, and Franko was just such a man. His outlooks were shaped by experience unattainable to her” (Todorovski 38). Slavica and Captain Franko are different in several respects, making evident that their characterization is linear and based on traditional binary gender divisions and double gender standards. Franko’s appearance corresponds to the stereotype of the charming and physically handsome older man: gray hair, blue eyes, a flat stomach. A blue captain’s uniform with golden buttons and golden-brown braids on its sleeves contributes further to his charm. In contrast, Franko’s sister Lucija, one year his junior, is described as “looking older.” Her completely gray hair suggests the kind, proverbial grandma, while Franko’s hair, which appears almost silver, lends him a “striking appearance” (Todorovski 12). The same gender pattern is applied to Slavica’s appearance. She is described as a petite, shy old lady, rosy-cheeked and with a pageboy haircut (Todorovski 21). Her stature resembles that of a 14-year-old girl, leading Franko to (patronizingly) call her “Bambina,” which she adores (Todorovski 21, 41). He is, in contrast, extroverted and charming. He compliments women and kisses their hands, makes lavish declarations, and does not allow them to pay for drinks – a repertoire of behavior representing a form of “soft patriarchy” (but not in the sense as interpreted by William Bradford Wilcox<sup>6</sup>). In the case of Franko’s relationship to Slavica, we see a form of gendered behavior in which the man takes a paternalistic and protective role characterized by elements of a traditional heterosexual relationship: flattery, making compliments, using his masculine charm, courting, treating women to drinks, and so on.

In contrast to the free, unpredictable, “real,” and authentic life of Captain Franko, Slavica’s life has been predictable, linear, and static. Their life narratives are imbued with so-called “spatial metaphors” (Bruner 703), which in this

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**6** | According to Wilcox, the term “soft patriarchy” describes “‘new men’ who take a more egalitarian approach to the division of household labor than their conservative peers and a more involved approach to parenting than men with no religious affiliation.”

case have a gendered component. Slavica has spent her life in the domain of a predictable and safe home, “restricted by duties and bored” (Bruner 703) and in constant self-denial. The sphere of “home” included not only the private sphere of the household and family but also her monotonous job at a local library. The first tragedy to change her life was the sudden death of her husband, Andro, at his workplace, while the second was the complete devastation of the family home – the house she and her husband had built together with enormous sacrifice – during the war in Croatia (1991–95) (Todorovski 38). Among the things destroyed at that time were all photographs taken in her youth – the symbolic testament to the fact that she had once been young: “Without them, it seems as though I was never young” (Todorovski 76). Slavica learned from life experience and circumstances that “many things in life turn out against our wishes” (Todorovski 38). Thus her wish to visit the coast had remained forever unrealized as she and her husband invested their money in building a house, educating their children, and paying for their children’s holidays. Now, she has no one to travel to the seaside with and no longer even feels like going. One of the reasons for this – unmistakably suggesting another internalized gender stereotype – is the belief that women cannot (or should not) visit the seaside alone (Todorovski 39). Observing and evaluating her life trajectory, Slavica cannot avoid the conclusion that (her) life is unfair and stupid (Todorovski 77), and comparing her experiences to those of Captain Franko, she concludes that all his “amazing stories” have been incomparably lovelier than her ordinary life: “It’s like [comparing] *The Arabian Nights* and work in a warehouse” (Todorovski 76). The anecdotes from the life of Captain Franko represent what Bruner calls “the real world”: an external, “demanding,” “dangerous,” “unpredictable” world, a “special place” of “excitement and opportunity” (703).

Slavica and Franko’s relationship takes a radical turn quite by accident. One day, Franko’s sister Lucija arrives unexpectedly for a visit just as Slavica is going to her room to fetch the figs she and Franko had planned to enjoy with some dessert wine (*prošek*) (Todorovski 88). Slavica returns after some time, and Franko appears relieved that the two women did not meet. However, a big surprise follows: Slavica tells him of her chat with the Home’s employee Snježana, which Franko at first interprets “as typical female gossip” (Todorovski 91). Here it is unnecessary to emphasize the gender stereotype produced by a patriarchal pattern that interprets every conversation between women (only) as an opportunity to exchange gossip. However, Slavica rejects his misconception, telling him that Snježana has told her that the Home is expecting a new resident: a retired sea captain, Jure Barić, from the coastal town of Šibenik. Slavica is especially excited about this news as she is looking forward to the three of them sharing stories about the sea voyages and the captain’s adventures (Todorovski 92). This is the moment when Franko must admit that he is not a real sea captain after all; in fact, he has spent his working life as a

bank clerk and later as a post-office employee (Todorovski 93, 94). Slavica is devastated by this confession for two reasons: first, she has been lied to by the first man she had grown to love after the death of her husband (suggesting a romantic aspiration in her relationship with Franko), and second, it turns out that the stories she had so enthusiastically been listening to were actually all in his mind (Todorovski 95). He also admits to her that his nephew Jerko, who supposedly has been sending him figs and *prošek* wine, does not exist. Rather, Franko himself had bought them at the market and a local wine shop (Todorovski 96). After an argument and putting an end to their communication, Slavica finds herself in unbearable situation – just like Franko, who yields to depression and despair (Todorovski 99). But she finally decides to step out of the role of a shy and invisible old woman and to meet a real sea captain and hear “true, real stories of the sea” (Todorovski 101).

She approaches Captain Jure Barić while he is watching the news in the TV room and begins to question him about his sea voyages, the ports he has visited, and the adventures he has experienced. However, she is disappointed by the drabness of Jure’s “maritime experience” (Todorovski 104). In his terse responses there are no signs of colorful adventures: he captained the ferry between Ancona and Split and was neither impressed nor inspired by the sea, nor did he yearn for long sea voyages or for other, distant seas. Moreover, Captain Barić does not even really look like a captain (for example, he does not smoke a pipe) (Todorovski 104). After this disappointing conversation, Slavica concludes that Captain Barić’s job had actually been as monotonous and boring as her own in the library. An unexpected intervention follows on the part of Professor Bučić and Doctor Lipovac, Franko’s two friends, who from the beginning have doubted the authenticity of Captain Barić. Since Captain Barić is the exact opposite of Captain Franko and diverges from accepted notions of a real sea captain – he has no stories to tell about his sea voyages nor “words of praise” for the sea; he does not sway when walking or have opinions on political issues – they conclude that he has a “dubious past,” is a “murky creature” and charlatan who they decide to debunk (Todorovski 106, 107). Here, a traditional gender stereotype again becomes evident: the duo accuse Slavica of “treachery” toward the man she loves, and they interpret Slavica’s “disloyalty” (Todorovski 106) again in a patriarchal frame: “a woman’s heart never owned the criterion of objective assessment!” (Todorovski 108).

These events ultimately lead to the restoration of friendship between Slavica and Franko. She approaches him with the idea that she needs him and must return to him because “Barić’s sea is no good” (Todorovski 113), despite the fact that Franko’s stories were just a figment of his imagination. However, the restoration of friendship returns a balance to their lives, and in the end this odd couple goes to the seaside together, which is significant in multiple ways: Slavica will finally get to see the sea, and their friendly relationship will enter a new phase.

## **LET ME TELL YOUR STORY: NARRATIVES ABOUT THE (RE)INVENTED PAST**

As human beings “we are made up of, engage in, and are surrounded by stories,” or more simply put, “our worlds are stories” – just like our lives (McLean et al. 262). As Kearney (3) writes, “food makes us live” but stories “make our lives worth living.” Stories of all kinds (fictional and non-fictional) and narrative forms (novel, autobiography, etc.) are instruments for creating meaning and bringing order to chaos (Kearney 3). Storytelling “is an integral and consequential part of daily life,” and narratives of all kinds are “significant sites of communication” because through making and telling stories, “people make sense of their experiences, claim identities, interact with each other, and participate in cultural conversations” (Langellier and Peterson 1). Therefore, narratives and storytelling have multiple functions (psychological, social, philosophical, ontological, for example); stories operate “as an expressive embodiment of our experience, as a mode of communication, and as a form for understanding the world and ultimately ourselves” (Brockmeier and Carbaugh 1).

Indeed, telling stories is a basic human activity: through a story, individuals explain themselves both to themselves and to others, thus providing themselves with an individual and communal identity (Kearney 3). Therefore, it is no exaggeration to say that “without a story, there is no identity, no self, no other” (Lewis 505). The “case” of Captain Franko is interesting to look at more closely because it raises some important questions about the relationship between the (re)construction of identity and the (re)creation of self-narrative. It is unnecessary to especially underline here that identity is one of the key categories in modern theoretical considerations and empirical interventions in the social sciences and humanities. Identity is a “central point of human personality” (Glińska 22), as well as a “social category that is understood as the self-definition of human being” (Glińska 20). Many contemporary sociological theories clearly show that individualism – as one of the fundamental values of modernity – has enabled the individual to “become the creator of his own biography (identity)” (Glińska 22), while postmodernity, stressing the importance of constant change and the uncertainty that accompanies it, has shown “that nothing in the world is finished, closed, finally defined” (Glińska 24). However, this volatility generated by continuous change does not hinder the tendency of identity to at least temporarily rest on some choices. Moreover, according to Zygmunt Bauman, it is precisely flexibility, volatility, ambiguity, and ambivalence that allow individuals, like tourists, to autonomously and freely decide when and with which fragment (personal or external) of the world they will get in touch (qtd, in Glińska 26).

Identity and narrative are tightly connected. In their presentation of the history of the development of narrative theory, Brockmeier and Carbaugh high-

light the important contribution of the theoretical considerations of Mikhail Bakhtin, especially of his study *Problems of Dostoevsky's Poetics* (1999). Bakhtin draws attention to the “multi-vocal and polysemic nature of narrative” and to the “structural analogies between novelistic discourse, life stories, and autobiographical memory” (Brockmeier and Carbaugh 7). For example, a “special sense of temporality, polyphony, and intertextuality” is characteristic of the modern novel but also of “the narrative construction of a life” (Brockmeier and Carbaugh 7). When we discuss the identity dimension of a narrative, many questions certainly arise, but one of them is especially significant when analyzing Franko’s character: What type of personality did Franko create in the life narrative that he daily recounted to Slavica?

After having considered Franko’s biography and his motivation for creating a new identity rooted in an imaginary (professional) past, we conclude that it would be too simple (and superficial) to declare him an ordinary liar (which does not mean that we would justify any form of misrepresentation). Franko’s situation is somewhat more complex. Namely, after spending his working life as a bank clerk and post-office employee, retirement intensified the issue of identity that was so important to him. Dissatisfied with life in Split, as well as with the fact that he had lacked the courage to realize himself professionally by becoming a sea captain, Franko decides to finally resolve the crucial life conflict between his “‘surface’ and ‘under-the-surface’ selves” (Berger and Luckmann 184) that made him spend most of his life in an ambivalent way: “I’ll be what I always wanted to, and couldn’t: a sea captain! But because of my age, I’ll be a retired sea captain” (Todorovski 95). Retirement encourages him to create an alternative subjective reality in which he is able to realize his full potential and create a new identity based on playing the role of a ship captain. Franko’s role is based on an idealized and romanticized – almost naïve – notion of a sea captain’s appearance and behaviour, and what his (professional and personal) life should look like.

The invention of a new identity is a form of identity strategy that relieves Franko of his feeling of dissatisfaction stemming from the inauthenticity of his existence and also allows him to establish and maintain a friendly relationship with Slavica (as will be discussed below). Bakhtin believes that every narrative has the potential for a “different story,” which is why there is a dynamic relationship between “actual stories about real life with possible stories about potential life” (Brockmeier and Carbaugh 7). The identity of Captain Franko is diametrically opposed to the identity of Franko the clerk. Captain Franko’s life is not trivial: he participates in the freedom and authenticity of “the real world” (Bruner 703) and experiences adventure, excitement, and suspense. His reinvented past stresses individualism and variations of a hegemonic masculinity: he is a courageous and well-paid sailor, a hero who navigates the world “according to ancient charts” (Todorovski 27), a loner dedicated and committed

to the sea, for which reason he has no family. As such, he is a sort of liminal persona, a wanderer always somewhere in between, who in direct contact with the infinity of the sea and the starry sky reflects on the human condition and his own position in the world. On the other hand, the narrative of his experienced and lived life is rooted in the contrasting sphere of “home” (Bruner 703): the monotonous and predictable life that Franko, at the moment of his confession, will call “stupid and boring” (Todorovski 94).

The narrative of his actual and truly experienced life reveals the average life of a clerk finally left by a wife tired of his stories and constant dreaming about sea voyages and ships (Todorovski 95). The lives of clerk Franko, librarian Slavica, and even of captain Jure Barić closely resemble each other, but there is one important difference: Barić never wanted anything else beyond what he had. He was not attracted to freedom, suspense or adventure, nor did he miss distant seas and unknown ports. On the other hand, unlike Slavica, who came to terms with her unfulfilled life with difficulty, though she was successful in her stoicism, Franko’s “subjectively chosen identity” became “a fantasy identity, objectified” in his mind “as his ‘real self’” (Berger and Luckmann 191). The identity intervention of rewriting personal history, made real through Franko’s appearance and his stories, represents a conscious switching of worlds (Berger and Luckmann 176) – the world in which Franko was a clerk giving way to the one in which he was a captain. However, in order to “confirm” this (in reality unrealized) imagination-based identity, public performance and its external recognition and validation were required. Franko had to (and could) only get the latter in a new environment where his true identity was not known. The Home offered such an environment, far from Split, where he consistently performed his new identity with the help of invented strategies of self-presentation (for example, smoking a pipe, wearing a captain’s uniform, serving dried figs and *prošek*, reading books about ships, keeping a sailor bag for his clothes) and through telling his life story. This literary figure demonstrates how “listening to and telling stories” is not only “a human communication practice” but also a “*performance*” (Langellier and Peterson 2). Berger and Luckman point out that “subjective identity is a precarious entity,” dependent on relationships with “significant others” (118). In Franko’s time in the Home, Slavica is the leading “significant other” (occupying “a privileged position”) (Berger and Luckman 171) with whom he talks mainly about his sea voyages, while to a lesser extent Doctor Lipovac and Professor Bučić also play this role.

The collapse of Franko’s identity as Captain and of his imaginary world – in which he, like a mythical hero, sailed distant seas, struggled with pirates in Burma, and got into a fight with drunken Portuguese sailors (Todorovski 53, 54) – occurs when Slavica learns that all his stories were fabricated and, unsurprisingly, feels cheated. Franko bases his defense on three arguments:

1. he wanted to be a sea captain as an expression of his authentic self;
2. he had told her things that she herself had wanted to hear based on her discontent and longing to indirectly participate in the fullness of the free and authentic sailor's life (proving that the goals of storytelling are connected with the "preferences of listeners" (McLean et al. 268): "In creating stories to please listeners, people create a certain kind of self in that moment that may have a lasting impact on the self" (Monisha Pasupathi et al. qtd. in McLean et al. 268); and
3. he raises the question of the relativity of truth and lies in everyday life, which seems to refer to the famous Thomas theorem, according to which "if men define situations as real, they are real in their consequences" (W.I. Thomas and Dorothy Swaine Thomas, qtd. in Merton 380).

The story also reveals that it is not only Franko who has secrets. For example, Slavica eventually admits that she has been living in the Home for ten years. Although she permanently repeats that her destroyed house is under reconstruction and she will be moving out of the Home in the following year, in reality the house has "long been restored" and she has not returned to Vinkovci out of fear of loneliness and due to the emotionally difficult truth that there is no place for her in the lives of her children (Todorovski 119). Professor Bučić, meanwhile, reveals to everyone that he has been posing as a philosophy teacher while he actually has a PhD in physics (Todorovski 62). While his roommate, Doctor Lipovac, thinks this a manifestation of "the highest arrogance" clad as false modesty, Professor Bučić explains that he had hidden his title to distinguish himself from Doctor Lipovac, as he believed that the life of "two doctors in the same room, would not be good for ... the polemic relationship" on which their friendship was based (Todorovski 129).

When in the end all secrets are revealed, Slavica and Franko restore their friendship and thus also Franko's identity as a sea captain and the world of his adventures, which it has been shown were of existential importance to both. Slavica concludes: "If all your life you wanted to be a captain, then be one, because you are. When will you be one, if not now? To me, only you are a real captain and only your sea is the right sea" (Todorovski 116, 117). This decision can be interpreted as a kind of emancipatory act, freeing the character of Slavica from the socially imposed norms, discourses, and limitations affecting the perception, decisions, and way of life of the individual. In making this decision, Slavica becomes an autonomous subject because – by accepting her "internal freedom" (Bakhtin 12) – she emancipates herself from the constraints of the external environment. The process by which we create a narrative of our lives (or some of its aspects), and thus shape our identity, answering for ourselves and others the fundamental question, "Who am I?," is neither simple nor easy. On the contrary, it is always about a dynamic, unstable, changeable, (spatially

and temporally) contextualized, relational, and partial construct in which lived experience and imagination, self-actualization and potentiality, past and present are intertwined, thus enabling us – from a freedom within – to communicate and present ourselves to ourselves but also to (in)significant others.

*Translated by Barbara Katić*

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# Home Care Home

## Reflections on the Differentiation of Space in Living and Care Settings

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*Isabel Atzl and Anamaria Depner*

“To thee, I’ll return overburdened with care  
The heart’s dearest solace will smile on me there.”  
“HOME SWEET HOME” BY JOHN HOWARD PAYNE, 1823

### CARE ROOMS

Care needs a place where it can be provided. This place is generally designed as a structurally limited space such as a room or building, located in a residential house or a care facility. Particularly when care becomes an essential part of life and is set up for the long term – in the case of chronically sick or older individuals in need of care – the spheres of living and caring tend to overlap. Space has to be created so that both appropriate care can be provided and the individuals receiving care can have the design and setup of their living space according to their personal taste and needs. Care and living therefore take place in a common space.

Nursing textbooks published in the nineteenth century describe in detail how patient rooms within the home should be designed and set up to be in line with the medical guidelines of the time. For the sick and elderly who were usually cared for at home during this time period, a very specific environment was to be created that was conducive to the well-being of the patient, from medical and nursing points of view. The main concerns for the design of patient rooms in modern care homes are structural and technical safety regulations. Consequently, as we will see, in the context of design, today’s textbooks still emphasize safety in the living and care environment. At the same time, these rooms are not only working spaces for caregivers in an institutional context but also the living spaces of people with very different life stories who are now living together in a new location.

The issues discussed in this chapter are based on work from an interdisciplinary research project<sup>1</sup> that focused on the role of objects in past and present nursing and care settings using an inductive approach. Although working on distinct time periods and with different methodological approaches, the authors soon discovered connections among aspects and themes that led to an intensive interdisciplinary dialogue, which we present the first results of in this chapter. It covers the range of conditions found in patient rooms in a family home in the German-speaking area in the nineteenth century and personal rooms in a care home today in Germany, including both home care and institutions, where people are cared for in the same rooms in which they live. How and to what extent have patient care and personal needs been reconciled in the past and today? And what (hi)stories do these hybrid rooms and their inhabitants tell?

To highlight these (hi)stories, we will first use an excerpt of a field report to provide insights into Anamaria Depner's current research. This special narrative form will portray an example of daily life in care facilities. At the same time, it will lead us to the theoretical and methodological framework, which will then be briefly presented. In the following section, we will use content from nursing care textbooks to contrast the design and setup of care rooms in both historical and contemporary settings. We will then outline the general themes and collate them as part of the results. Finally, we will recommend areas for further research and return to the central question of the influence the care situation has on the design and setup of the room and what it might look like to meet personal and nursing care requirements in the respective contexts.

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**1** | This article was written as part of this project called "Die Pflege der Dinge – Die Bedeutung von Objekten in Geschichte und gegenwärtiger Praxis der Pflege" ["Care and Things – Objects and their Significance in Past and Present Nursing Practices"] or, for short, "Pflegedinge" ["Care-related Objects"], see Artner et al. The project was supported by funds from the Federal Ministry of Education and Research from February 2014 through the end of January 2017 under the funding code 01U01317A and D. The sole responsibility for the content of this publication lies with the authors.

## INDIVIDUALS IN A CONTEMPORARY CARE HOME: A DOUBLE STORY<sup>2</sup>

### Scene 1a: Mr. Beck tells his story

The room we are going into next is occupied by two men. The bedridden man with the parchment skin (Mr. Adam<sup>3</sup>) is in the rear section of the room. The windows are high up on the wall and his bed extends into the middle of the room. The second resident (Mr. Beck) is in the front part of the room directly to the right of the door. Three photos hang on the wall above his bed. One shows him already at an older age together with a woman of about the same age, and the other two include two children, a boy and a girl. ... While Mr. Adam is being attended to, Mr. Beck addresses me, asking who I am, and we begin to talk. I learn that the two younger people in the photos are his children. He tells me that they are all already dead, both his wife and children who they had later in life. His daughter had been sick, but he doesn't say why his son is no longer alive. Mr. Beck says he is "the last one." He was no longer able to manage on his own, but here at the home, everyone is very friendly and he is thankful for what he has. He smiles warmly as he tells his story, and I listen and smile back and ask how long he has been here. "Quite some time. And we'll see for how much longer it will be," he answers and tells me that things could get better again and he would be able to move back into an apartment. Definitely not on his own, but maybe he would find a nice lady who he would get along with well. They do take good care of him here in the home, but it's just not the same. "I'm still doing well," he says as he looks over at the bed where his roommate is lying and adds that he would really like to live in a family again.

A man quite advanced in years shares a room with another resident whose health is much worse. Their living spaces aren't clearly separated and merge together; they constantly have the other person in view. In the above scene, Mr. Beck expresses his hope that he will soon be able to leave the care facility and return to his familiar environment, even if he is quite a bit older and would first have to find a wife, an apartment, and a home. He describes it as though it could very well happen in the foreseeable future and not like wishful thinking. The professional care provided by personnel in a care home and that of a wife or partner – without which, according to his own view, he wouldn't be able to cope – are, in his mind, two essentially different types of care. This distinction doesn't seem to be so important for Mr. Beck, although he does need support; instead, where, and connected to this from whom, he receives support is important to him.

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2 | The extracts below are excerpts taken from the research protocol by Anamaria Depner, 2015. For the research context see Depner, *Diskrete Dinge*.

3 | All names have been changed.

### **Scene 1b: The researcher reports**

Mr. Adam initially appears unresponsive and incapable of communication; the way he is lying in his bed with his mouth open and the expression on his face make it look as though he was far away, but when he notices that the caregivers have entered, he manages a smile and turns to gaze at us. He looks pleased. The caregivers begin with the nursing care routine. They first check to see if his absorbent pads need to be changed. Mr. Adam was given a laxative since he hadn't had a bowel movement for several days, but it hadn't yet taken effect. Then they roll Mr. Adam onto the other side, the two nurses working well together as a team. They ask him to "help them" and praise his cooperativeness. One of the nurses, in particular, Ms. Clauß, speaks a lot with the older man who is obviously still quite mentally capable, which is reflected in his facial expression. ... since Mr. Adams' skin has become thin and fragile, it requires extra attention. The special bandages meant to protect the skin and allow it to heal are no longer necessary since the situation has improved, but it would still be necessary to apply his cream regularly, at least once a day, Ms. Clauß tells me. ... While Mr. Adam is being attended to, Mr. Beck addresses me, asking who I am, and we begin to talk. ... After the two nurses are finished with their work with Mr. Adam and we have just said goodbye to the two men (Mr. Beck squeezes my hand warmly and says that I should come again), Ms. Clauß says suddenly, "It finally worked" ... and they both return to Mr. Adam. I'm told that the laxative had taken effect and am asked to wait outside as that was nothing for people without training. I leave, whereas Mr. Beck remains in his room.

While Mr. Beck relates things about his life to a stranger who had just come into the room with the caregivers, his roommate Mr. Adam receives care. Mr. Beck tells the story of his family while the caregivers apply cream to Mr. Adam's skin. Mr. Beck talks about moving back into an apartment while Mr. Adam's teeth are brushed. After the conversation with the researcher, Mr. Beck sits on his bed while the caregivers change Mr. Adam's absorbent pads after his laxatives had worked. This all occurs at the same time, in the same room, and in the same space. The room serves as living space for both Mr. Adams and Mr. Beck; it is where both men are cared for, the workspace for the caregivers, and the space where Mr. Adam relieves himself, is washed, and provided with further care. The important point here is that the room is used simultaneously in all of these contexts. This is also reflected in the furnishings. Their personal room in the care home is shaped by the design and set-up required for the care of the residents (Mr. Adam's bed is in the middle of the room so that proper care can be provided) as well as the presence of biographical elements (the photos of Mr. Beck's wife and children that remind him of his previous life as part of a family).

## CURRENT STATE OF RESEARCH AND METHODS

The simultaneous occurrence of two situations or states that stand in tension and cannot be resolved by “either/or” but instead can be described with a “both–and” approach can be understood by applying the concept of ambivalence. Recently, several scholars, including sociologist Kurt Lüscher and educationalist Miriam Haller, have discussed the concept of ambivalence in the context of identity-formation processes in old age. Ambivalence is presented as a potential key concept in gerontology (Lüscher and Haller). Lüscher and Haller are concerned with the experience of intrapersonal developments in old age as a function of more powerful and often differing images and discourses of social aging (for example, active aging as opposed to the elderly in need of care). Such ambivalences, however, can also be found in the spatial environment of the elderly in an institutionalized context, where a new narrative for personal identity concepts must be found in and through incoherent object groups.

In the cases we considered, the ambivalence is, in a simplified sense, brought about by the fact that professional care is performed in the same location where the patients live. In the case of care facilities, the place itself has been moved to the margins of society, where the usual rules do not apply. It is precisely because of a care home’s distinctive character as a place of professional support for those in need of care that the distinction between workplace and private zone cannot be maintained. But also in historical home-care contexts, professional requirements were imposed upon private dwellings. Fifty years ago, Michel Foucault proposed the term *heterotopia* for these types of social “ambivalent spaces” and at the same time called for these phenomena to be comprehensively researched in their various manifestations (for example, in prisons, care homes, gardens, brothels, and sanatoriums) because of their diagnostic potential for society. According to Lüscher and Haller, *ambivalence* is “defined as referring to the experience of vacillating between polar contradiction of feeling, thinking, wanting and social structures in the search for sense and meaning of social relationship, facts and texts, which are important for unfolding and altering facets of the self and agency” (5).

Does the arrangement of things, which must equally offer space for care and biographical elements, contribute to the fact that although Mr. Beck is content, he would articulate his desire to leave the residential care environment (“to live in a family again”)? How does the design of personal rooms in a care home affect the elderly people who live there?

The fact that personal things can be significant for identity in a multifaceted way has been shown in research over the past five decades in ever new ways and from the perspective of numerous disciplines. Pierre Bourdieu’s model of subtle distinctions does not head this list, but it is certainly

one of the most influential approaches to objects found in living spaces. In her research on life stories in East Indonesia, ethnologist Janet Hoskins even encountered biographical objects that can stand in as substitutes for people. The cultural psychologists Mihaly Csikszentmihalyi and Eugène Rochberg-Halton, psychologist Tilmann Habermas, and anthropologist Daniel Miller, among other prominent researchers, have substantiated the identity-creating function of personal objects in the context of the home. However, the potential that objects have to define personal space has not yet been given adequate consideration.

In recent years, the interrelationship and interdependency of (everyday) objects and spaces (Rolshoven; Pfaffenthaler et al.) have been addressed in German-speaking history and cultural studies, partly also under specific reference to the object-mediated spatial constellation in daily life (Depner, “Wie der Spatial”; Atzl, “Pflegeräume”; Keckeis, “Raum”; Oswald, “Lieblingsdinge”<sup>4</sup>). Living is seen here as an action that manifests itself in the interaction with personal objects that are used to divide a structurally defined space. When one actively exercises autonomy to arrange these objects, living areas are created. The focus on the identity of the individuals living there and their private needs and preferences is key. To summarize this notion, the philosopher Beate Rössler uses the concept of “local privacy,” something that is also addressed by Keckeis, “Dritte”).

From a historical nursing perspective, there has not yet been research on room design and setup in the care context, nor have relevant personal objects been examined from this academic perspective. At first glance, the latter is surprising since biographical work today is an important practical instrument used in modern models of care, in which high value is placed on the individuality and self-determination of those receiving care. In the sources that still exist from the past few centuries, the individual fate of patients has not been a high priority; the history of medicine and, to a lesser extent, the history of nursing have focused more on understanding the profession itself and its components rather than on patients. Patient histories used in research in the past two decades have attempted to place the focus on the individuals receiving care, but here neither room design nor objects have played a central role (Stolberg, *Homo*; Dinges et al.). In today’s nursing science context, personal and biographical objects are not explicitly considered in overviews of nursing

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**4** | The latter three sources are based on lectures that were part of the event titled “Raum Ort Ding: Kultur und sozialwissenschaftliche Perspektiven” [“Space, Location, Object: Culture and Socioscientific Perspectives”], workshop conducted by the working group *Materielle Kultur* [Material Culture] in the German Anthropological Association (GAA) and the Institute of Gerontology held at Heidelberg University on 20–21 Nov. 2014.



theory (see, for example, Meleis) or, for instance, in Erwin Böhm's psychobiographical care model. Environmental gerontology, however, has long emphasized that objects in the living environment should be viewed not only in light of their practical and safety-related aspects but also as personally significant objects (Saup; Wahl et al.; Oswald, "Subjektiv"; Beil). More recent studies from the field of ethnology also describe the features of the relationship between space, objects, and individuals in the context of institutionalized care (Löffler; Depner, *Dinge*). It is in this research that we clearly see the narrative potential of objects that are connected to biographically relevant stories and identity-forming events.

The theoretical basis for this research has recently proven to be quite sound, but not particularly elaborate. Instead of focusing on the social, communicative, or interpersonal space, which are themes that have often been examined in publications over the last few years, our research centers on living situations, the space required, and the design and setup of that space. This is surprising because the "spatial turn" – which has long been and continues to be influential – was a contributing factor to the establishment of the "material turn." When brought together with inspiring concepts from material culture studies, the connection between space, structurally defined spaces in particular, and objects not only is theoretically and historically promising but also offers opportunities for practical implementation in care facilities.

In the framework of the "Pflegedinge" interdisciplinary research project, we, along with our colleagues, have been focusing on care-related objects, which include all the objects that are purposely or unconsciously used in the context of care (Artner et al.). As established at the "Raum Ort Ding" interdisciplinary workshop in Heidelberg in 2014, they are also essential for setting up care rooms (Atzl, "Pflegeräume"). Objects always require space, no matter if it is for their use or storage. In the middle of the nineteenth century, when the objects used for care began to be mass produced, the question of where these things should be placed became pressing. Where should they be laid out? Where should measuring instruments, care materials, and increasingly specialized supplies be kept and stored? How close or far should they be located with respect to the place of care? To what extent do they contribute to the design and setup of the room where care is required? What specific impact do these things have on a care room?

## ON HOME CARE AND CARE HOMES

### Patient Rooms in a Family Home in the Nineteenth Century

In the nineteenth and early twentieth centuries, most older people were looked after and cared for in a home environment.<sup>5</sup> If they didn't have family, the only possibility was to consign them to poorhouses or hospitals, although by the beginning of the twentieth century, hospitals no longer served as multifunctional facilities (Murken; Verein für Krankenhausgeschichte). Older people who also needed to be cared for were to be found in the entire family setting. If care was necessary, the guidelines for optimal care included in nursing textbooks until the early twentieth century were to be followed. The design and setup of the room described in these written sources was the best possible situation recommended by doctors, but many people were certainly not able to implement it. However, a description of the theoretical ideal emerged to which caregivers could aspire. In addition, the first nursing textbook, which was written by Florence Nightingale, published in 1859, and well received in Germany, emphasized the importance of patient-room design and efforts to provide an adequate environment.

At first glance, it is surprising how much space – about a quarter – was allocated to these depictions in medical textbooks that date back to the beginning of the nineteenth century (e.g., Dieffenbach; Gedike). In the early twentieth century, such information was greatly reduced and found only in textbooks that also emphasized home care (e.g., Leo). For example, the ideal patient room derived from one of the first textbooks, written by the physician Johann Friedrich Dieffenbach in 1832, includes architectural aspects as well as the design and furnishings of the room. Beginning with the location (preferably in the quietest part of the house and facing east or south), the room should also be simple and practical to clean and disinfect, and, if possible, the windows and doors should not be opposite one another, in order to avoid drafts. The best option for heating was a tiled stove. If the elderly or sick patient agreed, the bed would be put in the middle of the room so that caregivers could have access from all sides (54–55). Ideally, the bed should have an iron frame. The choice of bed was of paramount importance for elderly and critically ill individuals for the following reason: “A patient's bed is their world – they live in it and cannot escape it. It is the first and last thing in our human life; newborns are laid in a bed and those who are dying do not like to leave their bed” (55, our translation). Horsehair mattresses, deerskins, pillows, bed covers, and foot supports were recommended in every case. Gas and oil lamps offered patient-friendly

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**5** | This remains true for German-speaking countries, where about three-quarters of all individuals in need of care are still cared for at home.

lighting, not too dark so that proper care could be provided, but not so bright as to disturb the person lying in the bed. An overbed table, side table, commode, and a comfortable upright chair with arm rests should be included, as should an ordinary table and chair. There should be an adjoining room where supplies that are not always needed or shouldn't be kept in the patient room can be stored, such as bandages and bedpans (30–69). Making it possible for the patient to read seems to have been important. For example, patients were offered reading supports and lamps (see, e.g., Böhme; Lees).

The recommendations found in textbooks did not discuss personal items in detail; the room design was based exclusively on medical and nursing care requirements; individual needs were not mentioned. The recommendations were for a room in a house that had to be set up differently or entirely remodeled. In this process the room took on a different character, and at the same time the patient or elderly person with limited mobility would no longer or hardly ever leave this room. Although the smells and noises of the house, its inhabitants, and the view through the window remained the same, the environment was changed from the original living situation. The need for care in all its facets imposed on the living area and created the ambivalence and heterotopia described in the research context here.

### **Personal Rooms in a Care Home Today**

Nursing textbooks today include far fewer recommendations on how to design and set up rooms in private homes for individuals in need of care. Instead, these texts focus primarily on the professional context of a care facility, and the design and setup of these rooms are addressed only marginally at best. The comparative example here (Menker and Waterboer) from a historic source emphasizes safety in the sense of how to best minimize tripping, falls, and sources of injury; it is thus representative of both current nursing instruction and classic gerontological literature in which objects are reduced to their potential role as aids or obstacles. To this end, the nursing textbook considered includes the following recommendations for private households: Special attention should be paid to ensure that the apartment or house includes enough handles throughout as well as a door viewer and an emergency call system. Steps or thresholds will need to be bridged with ramps, and dangerous carpets and cords should be removed (Menker and Waterboer 613). To reduce safety risks in care homes as much as possible, “mirrors,” “loud noises,” and “too many colors or patterns and color contrasts” should be avoided, a “maximum freedom of movement” should be ensured, and rooms should be marked with “familiar symbols and pictures” to facilitate orientation (613). Alongside the requirement established in 1832 that the room should be simple and easy to clean, today minimizing fall hazards and barriers is emphasized.

In various sections in modern textbooks under the rubric “Setting up the living environment,” we find more advice on how best to design and set up resident rooms. They should not be “lacking stimuli,” “bare,” or “depressing”; curtains, carpets, bed linens, and the like should have warm but subtle colors; pictures and photos can be useful in the design, as can “objects that have meaning for the person concerned” (Menker and Waterboer 378–79, 613, 704). Many passages emphasize the fact that it is important to have plenty of natural light as well as good artificial light. The position of the bed is repeatedly identified as relevant for well-being, stimulation of bedridden individuals, and also peaceful and deep sleep. Access for the caregivers and a sense of security for the people who are sleeping are problematized as possible conflicting needs when it comes to the positioning of the bed (581–82). In the context of this type of room design, both “stimulating” and “calming” effects are often desired.

Unlike the past, today we have a good understanding of how to put these principles into practice. What do these rooms look like, then, when it comes to their practical implementation? The middle of the room is usually left empty and the rooms are not carpeted. Individuals receiving care should have freedom of movement, and caregivers should have space to carry out their work with the help of aids such as a commode or lift. Bandages, absorbent pads, and other such materials are still (at least as much as possible) stored outside of resident rooms and brought into and out of the rooms on a nursing cart by the caregivers – another reason that good accessibility and a certain amount of free space in the room are necessary, if possible close to the bed. Beds that used to be fixed in one place have become mobile; they now have wheels and can be adjusted into many different positions, and they are no longer located in the middle of the room because greater consideration is given to the occupants’ habits and their need for a feeling of security when they are sleeping, as well as to changes in work procedures as a result of the increased mobility of the bed. If required, the bed can now be moved much more easily so that it can be accessed from all sides. As with the information provided in the historical sources, most beds today also have a significant inventory. In addition to blankets and pillows, a variety of materials are present to be used for positioning purposes and to keep the bed dry. Objects a resident uses often are placed together next to the bed, usually on a side table or nightstand. With Lawton (qtd. in Oswald, “Lieblingsdinge”), we can speak of an accumulation of important objects as “control centers.” It is precisely here that we find collections of objects that are frequently used, relevant to care, or of biographical or personal significance. A few additional biographical or personal items are placed on the walls of the residents’ rooms or, less often, on their bookshelves.

In summary, we can single out the following two aspects: first, the interior design found in the modern care facilities we visited as part of our empirical research follows the few recommendations found in current nursing books to

the greatest extent possible; and second, the current core issues related to room design and setup – for example, that proper care can be administered in the living area – correspond with the historical topics, even if, as we will see next, the content, implementation strategies, and common interest groups show significant differences. We would now like to discuss some of these points of overlap in more detail.

## POINTS OF OVERLAP IN INDIVIDUAL CARE-HOME ROOMS

On closer examination, a number of questions arise, for example, about involved parties and interest groups, power and knowledge distribution, distribution and implementation of areas of competence, and the right to privacy. At this point, we do not want to bring up general social debates and discourses or the general pursuit of political and economic interests that often are discussed without observing the particular situations. As a result of our inductive ways of looking at the significance of objects in nursing and care settings, we want to focus on the aspects that become apparent in each spatial situation and show them by comparing a remarkable similarity over times and settings. We want to shape these ambivalences and heterotopias in the past and today by using this very particular perspective. This approach is a fundamental part of home-care (hi)stories.

### Involved Parties and Interest Groups

Which parties exerted or continue to exert influence on the design and setup of care rooms? In the early nineteenth century, physicians first addressed and, most importantly, tried to influence room design and setup. Caregivers, the second group, were to implement these requirements as best they could and defend these against the third group, which includes other relatives, neighbors, and friends. If it was realized, this also meant that physicians gave caregivers authority within the hierarchical structure of the care situation.

Today, the parties involved in the design and setup of the living area of an older person in need of care are quite different. Physicians are no longer directly involved, whereas family members who are involved have even more influence. As we were conducting the surveys, we frequently heard that the objects in the room were placed or arranged as the family members had wanted. In Germany, there are also many structural, safety, and legal regulations, for example, in the form of *Pflegegesetze* (federal nursing-home regulations) and various *Länder-Heimrechte* (state laws). To expand on this topic would fill an entire book, as German bureaucracy is very well known for its attention to detail. It is important to keep in mind that with this development,

new abstract but powerful parties, such as a number of legal institutions, care organizations, health insurance companies, and their evaluating authorities (for example, home supervisory authorities) become involved in the design and setup of living spaces.

### **Power and Knowledge Distribution**

The historical literature primarily emphasizes the duty of care that caregivers are entrusted with. That duty is closely connected with the distribution of organized knowledge within the constellation of individuals involved in the care situation. The patient was considered to be in need of protection and was dependent on the help of the caregivers. In the best-case scenario, the caregiver took the patient into their care, while the physicians were responsible for the diagnosis and for conveying the necessary information to the caregivers, who then took this into account. In the textbooks, we read again and again about the danger of causing “a fatal cold” or “a fatal scare” (Dieffenbach 33) by not observing proper procedures or using care-related objects correctly. If a patient came close to dying because the caregiver failed to observe the procedures, this would undoubtedly result in the caregiver being morally accused, if not disciplined by losing his or her employment. In the nineteenth and early twentieth centuries, trained caregivers found knowledge in textbooks to enable them to properly observe procedures in order to eliminate fatal threats. However, in this early phase of the development of the caregiver profession, knowledge production was exclusively the domain of the physicians who produced the medical texts. The individual experience of the caregivers themselves was deemed unimportant.

It is the same today. Physicians have the competence to order the necessary treatment, and the caregivers are still the ones who know how to implement this treatment. In addition, there are now numerous guidelines and standards that these two groups must follow. In practice, however, the regulating institutions mentioned above are, along with the physicians, not regularly present at the caregivers’ place of work. When addressing the issues of power and knowledge, this must be kept in mind. The material logic of used objects in specific situations and the special characteristics of resident rooms often require that particular adjustments be made. In conversations and interviews with caregivers, we heard that this often resulted in uncertainty. Occasionally, instructions are unclear, and sometimes they are difficult to understand or are contradictory. Concern is heightened when the structural conditions of the rooms cannot be brought completely in line with legal requirements, for example, as in the case of safety regulations. The possible consequences for an individual’s own professional future or the evaluation of the facility are threatening and engender fear. In addition, the regulations for the use of aids and care-related

objects and the preparation, handling, and other interaction with these create uncertainty at times, and these regulations are followed with the utmost care. Ensuring proper use of these objects is a decisive factor in the design and setup of personal rooms in a care home.

## **The Historical Implementation of Areas of Responsibility**

Prior to the early nineteenth century, bedside medical care often involved a large group of people who gathered around the bed of the care recipient and discussed and negotiated medical diagnoses and therapeutic procedures. Neighbors, family members, healers, and sometimes several physicians all participated in this communication process (Atzl et al.; Stolberg, “Kommunikative”). Since caregiving was not yet a separate profession, physicians considered it especially important to train everyone who had a key role at the patient’s bedside in order to decrease the number of people involved in administering care. At the beginning of the nineteenth century, the situation changed and the medical and nursing care of the patient or elderly person was placed in the hands of specific individuals. Rest and a limited number of visitors became important, and the caregivers were charged with regulating these. But physicians maintained control, if not complete responsibility.

## **The New Right to Privacy**

Privacy, intimacy, and shame began to be mentioned more often at the start of the twentieth century and are now common themes in textbooks today. It is thought proper to carry out the various basic activities of our daily life such as food intake, elimination, personal hygiene, and sleeping in different, structurally separated rooms intended for these purposes. Some of these daily activities can be performed in company, whereas for other activities that would be unacceptable. Caregivers are encouraged to adhere to these social conventions in care situations as much as possible. But with regard to private space, the line is blurred between the living space of the care recipient and the workspace of the caregivers in order to accommodate the organization of work – and to the detriment of personal privacy.<sup>6</sup> In the extract from the research report included above, we see how a bedridden person receives food, has personal hygiene carried out, and even eliminates in the same room where he spends his days. And in the same room, feces are removed and patients are cleaned and sometimes dressed in new clothes. This overlapping of space – compared

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**6** | Research into the “commode” object by our colleague Lucia Artner is a prime example of how the positioning of care aids can change the understanding of space between a living and a working space (Artner and Böhringer).

to what is common practice in our society – culminates in the double use of a room that is home to two individuals. The room belongs to Mr. Adam just as much as it does to Mr. Beck. And that is also the case in the moment in which Mr. Adam is attended to by the nurses after he has had a bowel movement. Mr. Beck doesn't leave the room then; instead, he "stays in his room." There seems to be no struggle or contradiction between his privacy and Mr. Adam's.

But what qualifies a room as a private space? As Rössler argues, "Privacy isn't only created in rooms when I have authority over who is allowed to enter but also when I can organize the space for myself so that the objects in the rooms have a certain order and that specific objects are present that make the room have meaning for me, personal meaning" (Rössler 255–56). A large degree of "local privacy" that can be connected to a room the residents set up themselves is therefore crucial for a comfortable atmosphere. It is important that very specific, meaningful personal items that were selected independently, for whatever reasons, are present. The experience of the self and defining one's own individuality are elements of privacy and a comfortable ambience. Living spaces need room for private and personal (hi)stories as well as the identity of their residents.

But in the course of history, personal and biographical objects in resident rooms have been rare, and very seldom have they been chosen and placed by the residents of the rooms themselves. Place is found, in particular, for those objects that are needed or required to carry out nursing-care procedures, but even private things are often used for the purpose of care. In the inventory of personal rooms in a care home, what materializes is the history of the technical and professional progress of nursing care, not the history of the residents. Indeed, the latter seems to be interchangeable. It should be as simple as possible to make space in these rooms for the next person in need of care who moves in with their own life story – and as few objects as possible should have to be taken out.

Currently, "quality of life" and "well-being" (e.g., Kruse) are increasingly becoming the focus of research and are seen as an approach to working with care-home residents, especially with regard to people with dementia. Care homes, in line with current endeavors, should become more of a home in the sense of a self-directed "home sweet home" and not in the sense of an other-directed "care home." This can succeed only if the objects of self-narration that strengthen identity are provided with more space. It is essential that the residents are more involved in the selection and arrangement of these objects and that the normative-nursing or regulating-legal view puts aside its paternalistic entitlement.



## CONCLUSION

Comparing our research results reveals aspects that have considerable influence in the design and setup of care rooms in both the historical and modern contexts. The parallel is that care rooms in the past were and today still are geared toward providing the most ideal care situation and work structure and ensuring an efficient workflow. The main focus is the care “choreography,” which is clearly central and focused on the care needs of sick or frail older individuals. These needs alone seem to be emphasized, because both in the ideal situation of private rooms in a family home in the nineteenth century and in personal rooms in a care home today, the focus has been on proper nursing care. For this care, the meaning of which can be measured by economic means, the fate of the individual seems to take second place. Two hundred years ago, the focus was on improving the overall care situation for patients and developing guidelines to ensure adequate care. Today, the concerns include the cost of placing older people in living situations outside of the family, demographic developments, and the high demand for places in care homes, all of which have greatly influenced the design and setup of living spaces that must also serve as care rooms for every type of care situation. For the design and setup of these personal rooms in a care home, regulations and requirements from external institutions come before the individual’s daily living needs and habits.

In work situations with a medical focus, personal items have not historically been emphasized in the literature, even if care is being provided in private rooms. Today, personal things are ascribed the role of potential stimulators, but they are then pushed to the edge of rooms; sometimes, the only space to be found is on the walls. The fact that resident rooms are primarily workspaces for caregivers in an institutionalized context, but that at the same time they are also still private living spaces for people, can be seen in only limited form in the teaching texts presented – and therefore also in the discourse-forming and practice-formative media. Considering and researching the hybrid function of these rooms more closely from the perspective of the employees and especially the residents is an area that we see as promising future research.

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# Home, Hotel, Hospital, Hospice

## Conflicting Images of Long-Term Residential Care in Ontario, Canada

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*James Struthers*

“A client’s ‘home’ is wherever that person resides. It can be a private residence, supportive housing, retirement home, or just about anywhere except a hospital.”  
ONTARIO, BRINGING 1

“It’s been quite disturbing for us because everything here is set-up to create a home-like environment ... but ... a large number of our residents are admitted ... on the verge of palliative ... We’re not really set up for a palliative population.”

INTERVIEW WITH CARE HOME SPIRITUAL HEALTH MANAGER, 2014<sup>1</sup>

Few institutions have been surrounded by as much confusion, such gendered contradictions, and so many cultural anxieties as care homes for older adults, which bear the weight of cultural and economic uncertainties around population aging, changing perceptions of frailty and family ties, the meaning of dependence and independence, and fears of mortality. As one former care aide observes, “finding no one to blame for old age, why not blame those who house it?” (Tisdale xii). In their recent study *Residential Care Transformed: Revisiting the Last Refuge*, British gerontologists Julia Johnson, Sheena Rolph, and Randall Smith agree that “what people fear most is not residential care per se but ageing and the challenges of deep old age” (216).

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**1** | I wish to thank the project “Re-imagining Long-term Residential Care: an International Study of Promising Practices” (Principal Investigator Pat Armstrong, York University), funded by the Social Sciences and Humanities Research Council of Canada, for permission to use this quotation from an interview I conducted as a project co-investigator.

In this chapter I will explore a series of recurring narratives about care homes that featured prominently in policy discourse and in the media in Ontario, Canada's largest province, primarily during the post-World War II era. During these years, the modern old-age home emerged out of the shadows of its poorhouse origins as both a companion institution to the postwar hospital and an alternative to the family home as an appropriate site for the care of vulnerable older adults living out the final years of their lives. Neither purely medical settings nor "homes," long-term residential-care facilities continue to exist in the "somewhere between," which complicates their efforts to attract both broad public support and the sufficient funding required to provide a good quality of life for their residents and a rewarding working environment for their staff. How these competing stories first emerged within Ontario and how they continue to intersect will form the core of my discussion below. I will conclude by looking at the ambiguities and contradictions contained in some of the Ontario government's most recent policy documents on the future of long-term care.

### **"SELFISH CHILDREN"**

Old age and the institutional care of aging adults emerged as a policy problem in Ontario, as in the United States, in the last quarter of the nineteenth century (Montigny; Haber; Haber and Gratton). Several trends converged, by the 1890s, to create the perception of an old-age crisis. The first was population aging. Due to declining fertility rates and increased life expectancy, the percentage of Ontarians over the age of 60 rose from 4.6 in 1871 to 8.4 by 1901. The growing visibility of an aging population was also made more evident by the increasing proportion of all adults over 20 in Ontario who were also over 60. As Edgar-André Montigny observes, "one was more than twice as likely to encounter elderly people among the population as forty years earlier" (35-36).

As the numbers of adults over 60 grew, economic conditions for their working-age children also deteriorated, due to a sharp recession in the early 1890s. The result was an upsurge in demand, both from the aged without kin and from those whose families could no longer support them, to gain admission into Ontario's county poorhouses, which grew from only 9 in 1889 to 34 by 1912, in addition to 40 charitable city refuges also subsidized by the province (Williams 55). Increasingly, other categories of the dependent poor such as widows, the disabled, and children were also being rehoused in special institutions or programs of foster care. By default, the aged became the "leftovers" of the poorhouse, comprising 80 per cent of inmates in Ontario's Houses of Refuge and 70 per cent of inmates in its Houses of Industry. These were the elderly now most visible to the state. And due to the rigid admission policies

mandated for these facilities, they were seen as a population that was overwhelmingly decrepit, unproductive, and helpless (Montigny 98–99).

Why did so many of the poor now seem to be old?<sup>2</sup> And why were they demanding entry into refuges? The responsibility, according to provincial officials, lay with families, not the state. Old people, they argued, were being “foisted upon the government” in order to shift the burden of their care “from the home to the state.” Building more institutional care would simply “take away ... the filial obligations for the support of aged parents which is the main bond of family solidarity” (Montigny 32, 103). After 1912, the construction of new houses of industry or refuge virtually ground to a halt, despite a 218-percent increase in the proportion of the population over 60. By the mid-1940s, 10,000 needy aged were crammed into structures originally designed to house fewer than 5,000 (Williams 56–57). Creating a narrative of selfish families, however, allowed the government to justify policies designed to avoid spending more money on the problem.

## “REFUGEES”

From the 1890s until the 1940s, the fate of aging inmates in Ontario’s Houses of Refuge was bleak. Admitting to any “friends or family” able to provide care denied them the right to be admitted (Montigny 102). Since Houses of Refuge were located on working farmland outside towns and cities, they also physically segregated the aged from the majority of the population. Inmates lost their right to vote as well as their right to leave the institution without the permission of its superintendent. Living in dormitories of 10 to 18 beds, they also lost their right to privacy (Snell 39, 47; Struthers, *Limits* 56–57).

If physically able to work, they were required to do so, without pay, in order to help defray the costs of running the refuge. If they could no longer work, which became increasingly the case as the average age and frailty of residents rose over time, they were segregated within the oldest and most unattractive areas of the buildings, often basements or attics, which were renamed the “Old Persons’ Home” or “Old Persons’ Section” (DesRoches 64–65). If they misbehaved, or became “gravely disturbed mentally,” they could be confined to a locked and barred cell in the basement (Struthers, *Limits* 57). Married couples were not allowed to live together, nor were residents allowed to marry (58). The labels “decrepit” and “helpless” were used to describe older inmates in order to “justify [their] segregation” and to appeal to public sympathy and support. Due

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**2** | In fact this was an illusion. As Montigny notes, “contrary to common assumptions the vast majority of elderly people in late-nineteenth century Ontario lived independently and were capable of maintaining themselves” (52).

to their perceived maternal instincts, women took over the administration of these parts of the refuges whose residents were increasingly seen as “childlike” (DesRoches 64–65; Snell 46).

By the early twentieth century, many Houses of Refuge were given new names such as “Home for the Aged, Friendless, and Infirm” (Snell 47), but this rebranding, Cheryl DesRoches argues, “awarded neither additional status nor additional comfort.” It only acknowledged that these were places where “the old people are not expected to work if sick, or unable to work” (DesRoches 70). Before World War II, these homes never lost the stigma of their poorhouse origins. As one 75-year-old retired Ontario schoolteacher put it in 1925, when pleading to the federal government for an old-age pension scheme,

I do not want to beg ... Often the only resource for men who have lived useful lives ... is to go to one of ... those horrible, abominable institutions, the county poor houses ... those PLAGUESPOTS of the universe.... They may do for some of the feeble-minded and for sots, but certainly are not places for decent citizens. (qtd. in Struthers, *Limits* 50)

### **“A NICE HOMELIKE ATMOSPHERE”**

By 1945, demographic changes within Ontario and new conceptions of social citizenship emerging out of the Depression and war years intensified the demand for different approaches to the care of vulnerable older adults as the percentage of the population aged 65 or older ballooned from 5.5 to over 9.0 between 1901 and 1951. The answer to their needs could no longer be the poorhouse. Inspectors’ reports in 1946 revealed more than 500 frail elderly crammed into “temporary” beds in the attics, basements, and hallways of the province’s houses of refuges, all of which had long waiting lists for admission. “Upon entering these [homes],” one complained, “the first impression was an overpowering odour ... of human excrement, body odours, boiled cabbages and strong disinfectant. With the wooden floors, cloth upholstery on the furniture, poor plumbing and lack of ventilation it was almost impossible to keep down odours” (Struthers, “Nice” 337). In Toronto, municipal officials noted that while the city’s population had quintupled since 1900, institutional shelter for the elderly had only doubled. Out of this crisis had emerged the “rise of unsupervised, commercialized accommodation” for those with “minor and serious illnesses common to aged people.” Public-health officers reported growing numbers of the elderly “lying sometimes in filth and squalor in a rooming house with no one to feed or attend them, sometimes in rooms so cold that they cannot be bathed by a visiting nurse and no hospital will accept them” (Struthers, “Reluctant” 172–73).



Other changes also heightened the search for institutional alternatives to either poorhouses or family care of the aged. By the 1940s, over 40 per cent of the Ontarians aged 70 and over would be collecting means-tested provincial old-age pensions, first made available in 1929. In 1951, their numbers more than doubled when a universal old-age pension of \$40 a month became available for all Canadians aged 70 and over, a change that greatly expanded the market for sheltering older adults. A housing crisis in larger cities such as Toronto also reduced the ability of families to take in bedridden aging parents (Struthers, "Reluctant" 172–73). As a result, by the 1940s, government officials were no longer blaming "selfish and ungrateful children" for abandoning their familial responsibilities. "With the best of intentions," they conceded, "younger members of families are finding it increasingly difficult to maintain the older members who have not been able ... to look after themselves" (Ontario, *Caring for the Aged*; Davies, *Into the House* 102). The increasing employment of married women throughout the 1950s also complicated the situation. As newspapers pointed out, coping with the chronic illnesses of the aged "requires almost constant attention and care which the busy housewife of today feels she cannot provide while looking after her own children or working at the same time" (Struthers, "Reluctant" 173).

Over the next three decades, two new policy narratives around the shelter and care needs of Ontario's vulnerable older citizens took shape. The first focused on the growing backlog of hospital "bed-blockers" and the greed of private nursing homes. This was a policy discourse shaped by a search for regulation, safety, cost savings, and efficiency. The second centred on the creation of a new welfare state, a visible symbol of which was abolition of the poorhouse and its replacement by a rapidly expanding provincial network of public and charitably owned and operated Homes for the Aged. This was a narrative shaped by images of comfort, dignity, happiness, and "home."

"Home dreams" of privacy and comfort for nuclear families were extremely compelling for the generation of Canadians emerging out of the years of Depression and war, and they fuelled the rapid expansion of the suburban experience (Strong-Boag). One of the by-products of these "dreams" for postwar politicians and social planners was the desire to eradicate the old Victorian poorhouse and replace it with a "reformed old age home ... fit for the newly minted 'senior citizen.'" It would be a modern, single story complex, decorated inside with light paint rather than dark stained wood. Communal areas would bring together residents for social events rather than merely for meals. All of this suggests a middle-class family home" (Davies, "Renovating" 162).

As Canada's wealthiest and most urbanized province, Ontario was at the forefront of this campaign. In the two decades following the passage of its "Homes for the Aged" Act in 1949, the province and its municipalities spent \$110 million constructing 89 modern homes for the aged, to care for more than

15,000 residents. Churches, ethnic communities, and other charitable organizations accommodated another 12,000 within 92 non-profit institutions. Over the 1960s alone, the annual cost of institutional care for the aged would jump from \$70 million to \$455 million, and with 8.9 per cent of its 65-and-over population living within institutional care by the mid-1970s, Ontario's rate of institutionalized elderly was 75 per cent higher than that of Great Britain and 41 per cent greater than that of the United States (Struthers, "Nice" 335; Forbes et al. 43-44).

The key significance of the province's Homes for the Aged initiative lay in its recognition that medical and social barriers to independent living rather than destitution should form the principal criterion governing admission. The intended clients were older Ontarians from all walks of life, not simply the poor. Once admitted, all "residents," as they were now called, would be treated equally as "paying guests", whether their care was subsidized by a local welfare department or came out of their own, or their children's income. The province's Conservative welfare ministers explicitly underscored the symbolism of this change at ribbon-cutting events held to celebrate the opening of the new facilities across the province during the 1950s and 1960s. "This ... is not a poor-house where unwanted people of the community are placed," W.A. Goodfellow pointed out at one such event in 1954. Instead, he and his successor Louis Cecile likened Ontario's new "ultramodern" homes for the aged either as dwellings that "match the finest of hotels" or as places where aged citizens could "enjoy all the physical comforts of a family home." In the new world of the postwar welfare state, families should no longer feel shame in seeing their aging parents in care homes. "The attitudes today are entirely different," Cecile proclaimed in 1962. "When an aged person cannot live in a private household, the family recognizes the Home for the Aged as a public service available to everyone ... The elderly person accepts the Homes as the best place in the community for his care and comfort." Or as the president of Ontario's Association of Homes for the Aged boasted in 1967, "twelve years ago it was unusual for families to place a relative in a home ... Today it seems to be a status symbol" (Struthers, "Nice" 337-38). Built mostly as 100- to 300-bed single-storey facilities, with three or four wings radiating out from a central core, they were located most frequently on the suburban fringe, often on farmland formerly occupied by older Houses of Refuge. Sleeping two or four to a room, they were still clearly institutions, not homes or hotels. But their open style, attractive colour and lighting schemes, spacious reading and television areas, tuck shops and beauty parlours, restaurant-like dining rooms, and new emphasis on recreational and physical activity provided a fitting architectural symbol of the entitlement of Ontario's pensioned citizens. Unlike the Houses of Refuge they replaced, the aim of these Homes for the Aged, according to government spokesmen, "was not to preserve a mere existence but to promote happiness" (Struthers, "Nice"

338). Gone were the “Superintendents” and “Matrons” of the older poorhouse, to be replaced by a new cadre of female professionals working as nurses, social workers, nutritionists, and physiotherapists, as well as occupational therapists whose goal was to “add life to years rather than years to life.” As Megan Davies points out, “with their special nurturing qualities and their cultural connection with ‘the home,’ women were seen as essential in a modern, compassionate institution for the aged.” At the same time, the emphasis on their maternal “nurturing” skills, combined with the absence of male employees, also underscored “the secondary status of these facilities and the ageist equation of the elderly with children” (Davies, *Into the House* 93–94).

For the first thirty years after the war, Ontario’s homes for the aged also struggled over the question of how much medical as opposed to “social” care they should or could provide. Throughout the 1940s, Ontario’s hospital infrastructure, which had not grown since the 1920s, struggled to find beds for “even urgent [acute care] cases ... because there are so many elderly, helpless, sick, occupying beds, living and boarding in these expensive institutions and for whom no place is available when they are ready for discharge,” Toronto health officials and physicians complained in 1947. “They just remain in hospital and keep patients out for whom something could be done.” The solution was to build “a low cost home for the aged.” In response, the Ontario government mentioned the need for accommodating a small proportion of so-called “bed-care” patients in its 1949 “Homes for the Aged” Act. “We feel this will be a great saving to the taxpayer,” its welfare minister argued. “These chronically-ill, bed-ridden persons need only bed-care, not the active valuable bed-space they have been taking in general hospitals” (Struthers, “Nice” 338–39). But the number of beds and the degree of medical care to be provided was never clearly defined. Homes for the Aged were specifically intended as “social care” rather than as “medical” facilities, which is why they were placed within the jurisdiction of the Department of Public Welfare rather than the Department of Health. Few issues would become more blurry over the next 30 years than determining the precise medical boundaries separating Homes for the Aged, on the one hand, from local hospitals and/or private nursing homes, on the other.

The principal criterion for admission to a home was proof that applicants were “incapable of looking after themselves in the community and require care.” However, the definitions of “incapable” and “care” could be elastic, ranging from frailness, physical disability, mental confusion, incontinence, or the inability to shop, cook, clean or climb stairs, to simply difficulties in finding an affordable place to live. The starting assumption, however, was that most clients would be able to walk through the front door. The 1952 brochure advertising one new home, for example, described a “home for elderly citizens designed to accommodate ... those who are self-reliant and active.” Out of

this home's 110 beds, only 17 were set aside for "special care due to physical or other infirmities." Similarly, when Toronto's first 700-bed Home for the Aged, renovated from a former veterans' hospital, opened in 1949 on a supposedly temporary basis, in order to help the city cope with an acute-care hospital-bed shortage, its director nonetheless protested that to devote more than one-third of its capacity to the care of the bedridden "would be in effect to change [its] character ... from predominance of ambulatory residents to that of the infirm" (Struthers, "'Nice'" 340). Seven years later, the city built a new 625-bed special-purpose home for the aged, on farmland 60 kilometres away from the downtown core, so that senile and bedridden residents from its other six municipal homes could be relocated in order to avoid compromising the "homelike atmosphere" of these other homes (CUPE). More than 200 of its first residents came from the original downtown Home for the Aged (which remained operating until 1981). Segregation of the senile, either in small separate wings in newer homes or in a 625-bed "special care" home, government officials maintained, was necessary in order to "shield ... from the sights and sounds of sickness and senility those who were in a better state to appreciate their surroundings and use the recreational areas, the craft and hobby rooms, gardens and chapel" (Williams 60). New semi-professional female staff in these homes also preferred to deal with "ideal" residents who were "willing and able to participate in therapeutic and recreational activities." Those perceived as "not treatable" were thought better fitted for life "in a custodial institution" (Davies, "Renovating" 172-73).

The new Homes for the Aged program did have its critics. Some argued that "the old folk have been placed in the beautiful glass and brick tombs outside our cities, their precious privacy invaded, and their right to make their own plans taken from them" (Gillen). Social workers specializing in the problems of old age also argued that "communal care rather than institutional care ... located in the actual neighbourhoods where these folk have always lived" was a more humane approach. Citing European examples, Toronto's Welfare Council in 1948 called for the construction of "co-operative homes to accommodate couples as well as single people, apartments for old people as part of public housing projects, [and] apartments specially designed for the convenience of older people," to be located not on the outskirts of the city but "close to centres of activity which include shopping sections, churches, transportation, and theatres," so that the elderly could feel they "belonged to the community and had responsibilities" (Struthers, "Nice" 342-43). These criticisms and alternatives, although prescient, would not be taken up by local and provincial governments in Ontario until the late 1960s and early 1970s, when federal government funding for seniors' housing became available on a sustained basis (Bacher; McMahon).

Homecare was also suggested as a better alternative. As Toronto's largest newspaper argued in 1951, the province's Homes for the Aged program "promote[d] huge and costly institutions which before long may become obsolete" and which too often were "being put up in the country, far from familiar interests." Why not look to British examples as an alternative and build "self-contained apartments or co-operative houses" for the aged combined with "community social services – home nursing, domestic aide, and personal case work and recreation to ensure comfortable and secure independence of aged persons living in their own apartments, flats, or lodgings" (Struthers, "'Nice'" 343)? At Ontario's first Conference on Aging, held in 1957, such concerns were voiced repeatedly, but they fell by the wayside due to major changes in provincial and federal shared-cost programs that same year. In 1957, Canada launched a universal hospital-insurance program that excluded federal funding for homecare as an insured service. The next year, the federal government also allowed older adults institutionalized in special care homes to be included, as "unemployables," for a cost-shared subsidy claimed by provinces under the new Unemployment Assistance Act, which provided relief to the jobless not eligible for unemployment insurance. By 1962, 21 per cent of Ontario's funding received through this legislation went toward supporting the care of the elderly and disabled in such homes. These decisions intensified the biases in favour of institutional rather than community-based approaches to caring for vulnerable older adults (Taylor 129–31; Struthers, *Limits* 190–91, 353). Homecare and assisted-living alternatives, first put forward in the 1940s and 1950s, would return as significant policy responses to the emerging fiscal crisis in hospital and long-term residential care only from the mid-1980s onwards (Baranek et al.; Struthers, "No Place").

Despite these criticisms and shortcomings, the construction and expansion of Ontario's Homes for the Aged during the 1950s and 1960s represented a high-water mark of "positivist" public perceptions of the old-age home as an innovative and progressive development within the postwar welfare state (Davies, "Renovating" 156). As one civil servant long engaged with the program wrote, in looking back on this era decades later, these "well-built, almost luxurious group homes ... each a local showplace in civic services ... [were] expressive of the most up-to-date and benign ideas concerning the quality of group living" (Williams 65). To Ontario's provincial treasurer, in 1964, the program also symbolized "the tribute which the present pays to the past. It is a *concrete* expression of the younger generations of citizens honouring their fathers and mothers" (Struthers, "'Nice'" 346; emphasis added).

## **“RELUCTANT PARTNERS: NURSING HOMES AND HOSPITALS IN ONTARIO”**

A year after the passage of the Homes for the Aged Act, a report released by Ontario's Health Survey Committee revealed that there was “a shortage of 10,500 acute treatment hospital beds across the province,” a situation that government officials deemed was “nothing short of a tragedy” (Struthers, “No Place” 392). A major cause was the growing number of indigent “older men and women, disproportionately elderly, and unable to receive convalescent care at home,” who were suffering from chronic cardiovascular, respiratory, and digestive problems. Their long-term “bed-blocking” was keeping self-paying patients out of local hospitals, thus eroding their fiscal integrity (Gagan and Gagan 83–86).

During the previous decade, Toronto, where the problem was most severe, had begun improvising its own solution. Starting in 1941, the city started to subsidize the discharge of elderly patients, at the rate of \$40 a month, about half the cost of their hospital care, from hospital indigent wards to selected private nursing homes. By 1947, this “temporary” program, which started with only 30 patients, was now paying for the care of over 600 aged in private homes (Struthers, “Reluctant” 174). But what kind of care were they getting? No one really knew. “[S]ome of them provide satisfactory care and some doubtful care, but under present circumstances adequate or effective supervision is impossible,” city officials confessed in 1946. A major scandal that same year, uncovered by Ontario's Old Age Pension Commission (OAP), forced the city into action. In one Toronto home, the OAP reported, 36 pensioners had died over a two-year period, a mortality rate double that of the city's Hospital for Incurables. When a suspicious pension official visited the home to find out what was going on, he discovered a disturbing scene: “Practically everyone in the house had severe colds, all the old people were coughing and one ... was very ill in bed with pneumonia. A slim, frightened looking person had two black eyes and a badly swollen face.” Another elderly lady had a “bad bruise on the left temple” and “blood ... oozing [from her] stocking from the knee to the ankle.” Further investigation revealed a home swarming with cockroaches and packed with 35 sick, elderly patients, locked in, seven to a room, where door-knobs had been removed so doors could not be opened from the inside. Six men were sleeping in the basement, five more in the attic. In response, Toronto's city council passed Ontario's first by-law requiring the registration, licensing, and inspection of private nursing homes. Lacking enforcement, it was largely a symbolic gesture. Unlicensed homes continued to operate and even to receive per diem stipends from the city welfare department for the care of indigent, elderly patients. Since hospitals and municipal homes for the aged already had

long waiting lists, Toronto officials confessed, there was little else they could do (Struthers, "Reluctant" 175-76).

Ten years later, not much had changed. Only a dozen cities had enacted nursing-home by-laws, which, health officials agreed, were "not in accordance with any real standards." Few homes provided much more than room and board, "with practically no nursing care of a skilled type." Local Medical Officers of Health seemed "generally [to] show little or no interest in a Nursing Home," provincial officials conceded by the end of the 1950s. Their hands were tied. "We know very little about the exact number or kind of nursing homes which exist," nor was there any commonly accepted definition of what they were. Most were unlicensed, but they could hardly be closed. "What would we do with the patients if it were decided to close them?" a public health officer asked (Struthers, "Reluctant" 177).

Ontario's 1957 Conference on Aging provided a forum for action. Over 150 private nursing home proprietors attended and two years later organized themselves into the Associated Nursing Homes Incorporated of Ontario (ANHIO), the first provincial lobby group for their sector. Over the next six years the ANHIO would take the lead in successfully pressuring a reluctant provincial government to license, regulate, and publicly fund for-profit care homes across the province. Three changes were crucial to their victory. The first was the province's entry into Canada's new national hospital-insurance scheme in 1959, which provided Ontarians with insured access to hospital beds on a universal basis, a major new entitlement that only exacerbated the problem of aging hospital "bed-blockers." As Ontario's Health Minister asked, "When do they stop being a patient who is chronically ill and in need of ... hospital care, and when do they become a patient who is essentially a ... custodial care? ... I cannot see how these can ever be brought into such a hospital care insurance plan." In response, the Ontario Hospital Insurance Commission contracted with 48 private nursing homes to outsource the care of chronic and aged hospital patients. The more provincial health officials began to learn about private nursing homes from this new partnership, however, the less they liked them. "Conditions in the majority of them [are] dreadful," the health minister warned Ontario's premier in 1959 (Struthers, "Reluctant" 178).

The second change was the previously mentioned extension of federal funding, under the Unemployment Assistance Act, for the social care of unemployable elderly welfare patients in private nursing homes. This development, an Ontario government study revealed, created a major stimulus "to the opening of many ... homes with the proprietors, sometimes with no previous experience and few qualifications, applying for licensing" (Struthers, "Reluctant" 177). The third was the impact of the Ontario Legislature's Select Committee on Aging hearings in 1964-65, which shone a spotlight on atrocious conditions within private care homes. As the president of the newly formed ANHIO testified,

some operators were making “profits as high as 30% to 40% in homes where blind patients were served the scrapings off the plates of others.” In others, record keeping was so poor that the proprietors “[didn’t] even know how long some patients [had] been there.” As for medication, “in most cases there is little or no control” (179).

In Ottawa, witnesses from Ontario’s non-profit care-home sector, testifying before the Senate of Canada’s Special Committee on Aging, said that these new government subsidies for private nursing homes were only “financing public psychological slums” in which people “sit ... and rot by the thousands” (Struthers, “Reluctant” 180). The impact of this damning testimony created a firestorm of negative newspaper coverage that pushed the provincial government into passing the Ontario Nursing Homes Act of 1966, creating a provincial licensing, inspection, and regulatory regime through the Department of Health for all nursing homes in the province. For the largest private operators within the ANHIO, this was a key policy victory. Regulation promised to bring order to a chaotically expanding sector. It also cemented an uneasy partnership between private enterprise and the provincial state to ensure that their profitability could be reconciled with the government’s fiscal priorities as well as with the long-term care needs of the aged.

Once safely under the umbrella of state licensing and regulation, private care home entrepreneurs launched a long-term strategy to place themselves on a level playing field with the charitable non-profit and public homes for the aged sector by demanding ever higher per diem patient subsidies, to the growing exasperation of Ontario’s health minister. “[S]ince the province got into the business of regulating nursing homes they have constituted themselves a pressure group to beat the Government over the head,” he complained to the premier in 1967. Two years later he was even more disgusted: “I have learned to my bitter sorrow that they are concerned about one thing only, making as much money as possible and giving as little as possible in return to the patients ... [T]he sooner this is gotten into on a public basis, the sooner we will be able to provide good quality health care for this segment of our population” (Struthers, “Reluctant” 181).

The confrontation came to a boil at the end of the 1960s, after a period in which the number of private care-home beds leaped from 8,500 to 18,200 following the passage of the province’s nursing-home legislation. The industry was simply growing “without rhyme or reason” as new operators rushed into the sector and began building homes “before we know anything about it,” Ontario’s deputy health minister complained. Half had been in business less than six years, and the health officials charged with overseeing them confessed that their own quality of knowledge about the sector was little more than an educated guess (Struthers, “Reluctant” 181). In the summer of 1968, private-sector care-home owners in Toronto threatened to evict all their subsidized welfare patients unless the city agreed to a 47-per-cent increase in the per



diem patient subsidy from the existing \$8.50 to \$12.50, as recommended by a private consulting-firm report commissioned by the ANHIO. City officials, in response, threatened to move them all to care homes outside the city which would accept the existing \$8.50 rate. Outraged residents refused to be moved away from their families, friends and familiar surroundings and their resistance attracted widespread public and media support. Toronto would be “ill-advised to consider ... shipping the old folks out of town,” a leading newspaper commented. Repeating a widespread exaggeration, the editors argued, “This does not seem too far removed from the traditional Eskimo [*sic*] ceremony of placing the old and infirm on a small ice-floe and leaving them to drift away” (qtd. in Struthers, “Reluctant” 183). Eventually a compromise was reached over a new per diem rate, but the ugliness of the incident was a harbinger of the difficulties of reconciling caring with profit.

Over the next four years, demands grew for bringing nursing-home care into Canada’s new universal Medicare legislation, which Ontario’s Conservative government only reluctantly joined in 1969. For three years Ontario resisted the idea, arguing that it would let families off the hook for the care of their own parents. Why should taxpayers underwrite “by grant or insurance ... the maintenance of the aged in facilities of some sort, when the families cannot, or will not, any longer maintain them?,” Ontario’s health minister asked. “Too often, it is concluded, since an old person has to spend much time in bed and have his personal wants and needs attended to by others, he should be kept in hospital. This is wrong.” Here lay the crux of the matter. The need for hospital care was a medical issue, decided by doctors, so it should be an “insured” benefit. However, care in nursing homes, deemed mostly “custodial,” seemed to make it a means-tested welfare benefit, not an insured right. But in practice were the boundaries that clear-cut? Not according to Ontario’s care-home operators. As they argued, in a brief to the Senate Committee on Aging, the difference between “chronically ill care” covered by health insurance and “ordinary chronic care” within nursing homes was “so indistinguishable as to be hardly discernible by the experts, let alone the uninformed public” (Struthers, “Reluctant” 184).

By 1972 their view prevailed when, prior to an election, the government agreed that nursing-home care would be included within the province’s medical-insurance scheme through a separate Extended Care Plan subsidizing medical, but not residential costs. With its inclusion under public health insurance, the private nursing-home sector achieved its most important victory. Under this new umbrella the industry grew by leaps and bounds after 1972, transforming itself, within five years, from mostly small, single-operator homes of less than twenty beds into highly profitable 100- to 200-bed facilities, owned by corporate chains. By 2004, the for-profit sector would be responsible for 60 per cent of the homes and 54 per cent of the beds in Ontario’s long-term residential-care sector (Ontario, *Commitment* 90).

## **“BUILDING A CULTURE OF COMPLIANCE”**

From the mid-1970s until the late 1990s, the rapid rate of expansion in Ontario's long-term residential-care sector slowed dramatically. Faced with growing budgetary deficits and capital shortages as economic conditions worsened throughout much of this period, Ontario's Conservative politicians, who governed the province until 1985, were content to let the private sector finance the costs of building most new nursing-home beds. During these years, policy narratives about long-term care centred on more efficient and intensive care-home regulation as well as the impact of increasing longevity, frailty, and population aging on the culture and costs of care homes. Problems with inadequate nursing-home inspection, staffing, and management also loomed large, as periodic scandals rocked the public's trust in this sector. In 1977, Daniel Baum's bestselling book *Warehouses for Death: The Nursing Home Industry* provided a bleak portrait of Canadian nursing home life:

People are there to die. Once they walk through the nursing home door and take their rooms, they will not walk out again. They are stripped of their assets, given a small personal allowance, promised minimal nursing care, regulated severely in their routine and medicated to institutional compliance. In a very real sense they are encapsulated and warehoused for death. They are removed from the community and the community does not have to see either old age or death. (3)

This was a far cry from the celebratory descriptions of Ontario's Homes for Aged program in its first two decades. Newspaper exposés added to these images. In 1981, the union local representing 300 staff in Greenacres, Ontario's largest care home, which, as mentioned previously, was opened in 1956 specifically to house senile residents from other nearby homes for the aged, revealed degrading conditions of work and care for its almost 600 residents. Residents were being fed, toileted, and bathed in “factory-like” conditions; staff experienced the highest rates of injury of any home in Toronto. Equipment was “broken down”; there were such inadequate supplies of clothes, blankets, shoes, and socks for residents that “staff had to raid closets at home for shirts for the men and dresses for the ladies.” The home was grossly understaffed. Although its name “evokes images of a small and tranquil estate in the country,” the report concluded, “Greenacres is a large and far from peaceful place. It is not a ‘Home.’ It is an institution,” and one that was “in a state of crisis” (CUPE 2, 6, 8–9). The ensuing media publicity that followed the release of this report resulted in a major public enquiry. Three years later, 19 residents in a London, Ontario care home died from a serious outbreak of bacterial food poisoning, due to substandard conditions for food preparation. This prompted another explosion of negative media coverage of Ontario's long-term residential-care

sector, leading to growing public and political demands for an end to for-profit ownership. Concerned Friends, a new advocacy organization dedicated to long-term care reform, described long-term residential-care facilities in 1982 not as “homes” but as “sterile, friendless [places] ... lacking humanness and warmth, where old people sit and rock, stare at walls for most of their day or are led around by the hand like small children.” In 1984, a Canadian Medical Association Task Force argued that care homes should be “run on a principle of loving care, not tender loving greed,” and recommended that governments “move as quickly as possible towards the elimination of care for-profit institutions and establish non-profit facilities” (Tarman 76–83).

The Ontario government response was more bureaucratic consolidation and intensive regulation of the sector. Rather than address issues of who owned care homes, the province instead focused on more aggressively enforcing a culture of “compliance.” Annual inspections of care homes were mandated, and the reports were made public. Resident councils were promoted. A Residents’ Bill of Rights was introduced, which included “freedom from mental and physical abuse” and “privacy.” Complaint-reporting mechanisms were expanded and made more transparent. Nursing-home owners were required to identify their directors and owners and to release their financial statements so that the public could see how much revenue was spent on residents rather than in dividends for shareholders. A new category of “compliance officers” was created to advise care homes on how best to meet new and more intrusive Ministry of Health standards. But the question of private ownership of care homes itself was left unaddressed by both Conservative and Liberal governments of that decade (Tarman 82–88).

Instead, in response to a court challenge and more aggressive lobbying from the private care-home sector, in 1993 per diem government funding for privately owned, charitable non-profit, and public care homes was made identical by Ontario’s left of centre New Democratic Party government, the unexpected winners of the 1990 provincial election. Since all homes now had to meet the same, more highly medicalized requirements, their level of per-patient government funding should also be equal, the NDP acknowledged. At the same time, the government also transferred all responsibility for care homes to the Ministry of Health, marking an end to separate oversight of municipal Homes for the Aged and non-profit charitable homes by the Ministry of Community and Social Services. This was another major victory for the for-profit sector, (Tarman, 87, Daly, 44)

Care-home policy narratives from the early 1990s to the present have increasingly focused on fears around the costs of population aging as the baby-boom generation matures into old age. A major 2012 Ontario government report on aging makes no mention of private care-home ownership whatsoever, but instead it frankly warns that “our demographic challenge could bankrupt

the province,” in arguing for a moratorium on building new care homes. A new “Seniors Strategy” should “focus on helping older Ontarians to stay healthy and stay at home longer” through concentrating on homecare as the most fiscally responsible solution to population aging (Ontario, *Living* 5–6). Another report, from 2011, argues that Ontario is still relying “too heavily on acute care hospital resources and a culture that emphasizes ‘permanent’ placement of seniors in Long-Term Care Homes without appropriate consideration of the patient’s potential to improve or recover and be cared for at home with support.” As in the 1940s, aging “bed-blockers” clogging up provincial hospitals are seen as the most urgent problem facing long-term care (Ontario, *Caring for Our Aging* 6–7).

An intensified focus on implementing an “audit” culture in nursing-home management has also emerged, in which “hard” quantifiable measurements such as pressure ulcers, blood-sugar levels, incidence of falls, fluid intake, and incontinence are viewed as the key inputs for measuring the “quality of life” in Ontario care homes and for determining their level of funding. Reduced emphasis is placed on the “softer” and less quantifiable variables of relational and social care performed by staff, whose numbers, since 1996, are no longer regulated by any minimum standard (Banerjee and Armstrong, Daly). The extent to which care homes should be allowed discretion to imagine different approaches for delivering good quality care in a “home-like” atmosphere remains subject to debate. While one report argues for “tougher enforcement and swift compliance” as well as “clear, measurable, enforceable, resident-focused standards with enforceability ... being key” (Ontario, *Commitment* 5), another decries the impact of such a “compliance culture” on the ability of these facilities to be “homes”:

Many stakeholders told us that often this results in situations where staff focus on compliance-related administrative and process activities instead of on providing care. In addition, they indicated that time dedicated to resident care is diverted to compliance-related functions, many of which are related to documentation and other paper work. (Ontario, *People* 11)

The first narrative has care homes facing outwards to concentrate on provincial standards. The second looks inwards in arguing for more locally based decision making “building on the knowledge, passion, and commitment of staff, LTC home operators, residents, and families to the provision of quality care. They set the stage for a change in how LTC homes plan to use their staff resources to meet resident needs” (Ontario, *People* 29; Banerjee and Armstrong).

## CONCLUSION

From 1949 to 1972, the Ontario government believed it had a coherent story to tell about care homes for the aged during the only era in which long-term residential care was portrayed in a mostly positive light. It was an uplifting and gendered narrative about the virtues of social care in delivering comfort, dignity, and “successful” aging within a communal context that officials insisted was “homelike” and “luxurious.” This was also a story about Ontario’s postwar affluence, the earned entitlement of its “senior citizens,” and burgeoning municipal and provincial pride.

To make this “homelike” story work, however, the numbers of vulnerable older adults who were senile, bed-ridden, or in other ways profoundly “helpless” had to be kept to a minimum through being segregated either within or between institutions. It was also a story about care homes as legitimate sites for an enjoyable and non-stigmatized middle-class life pursued by “active” individuals getting along together within a “quiet and intimate” setting, with some paid female care help from the state (Williams; Davies, *Into the House*). The trade-off, within the setting of new postwar suburbs, was an architecture facing mostly inwards as a “haven” looking away from the “busy” community outside, echoing in a smaller way the broader postwar suburban “home dreams” also being pursued by the children of the care homes’ new residents (Davies, *Into the House*; Strong-Boag).

In contrast and in tension with this positive story was the rise of Ontario’s nursing-home industry during the same era, which was a more incoherent, unexpected, contested, and increasingly medicalized development. This was a narrative of unintended consequences, grudging regulation and inspection, and recurring scandal. And the end result was anything but “homelike.” Within these buildings, the type and quality of care remained in service to the overarching needs of Ontario hospitals to free up scarce beds, and to the dividends of a mostly profit-seeking industry. At bottom, this was also largely a story of “facilities,” not “homes.”

By the 1990s, these two parallel stories of homes for the aged and nursing homes had converged, symbolized by the takeover of the entire field by Ontario’s Ministry of Health (Daly, 44–47). It has increasingly become a narrative dominated by the themes of medical more than social care, in which relentlessly rising costs, overcrowded hospitals, and rising panic over population aging continue to be the dominant actors. Once existing on the margins, a new emphasis on “community” care has also been in steady ascent since the 1990s and now dominates state-centred conversations about “home” and “care” within the province’s policy discourse on how best to meet the needs of Ontario’s vulnerable older adults. A century after worried provincial officials first shone a spotlight on the growing “burdens” of old age within Ontario’s Houses of Refuge, family care and family obligations are once again back at the centre of a new government story called “Bringing Care Home” (Ontario, *Bringing*).

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**Anamaria Depner** graduated from the University in Bamberg with a Master's thesis in Cultural Anthropology on the constitution of indoor-spaces. 2014 she completed her doctorate at the University of Frankfurt/Main with an ethno-

graphic study on the human-objekt-relationship when moving to retirement homes. Since 2014 she has been working as an academic assistant at the Institute of Gerontology (University of Heidelberg).

**Laura Dunbar** left nursing to pursue literary studies at the University of Toronto. From 2014–2017, she was Assistant Professor of Composition and Professional Writing at Concordia University. She's currently working on a second doctorate in Applied Linguistics at Carleton University.

**Sherry L. Dupuis** is Professor in Recreation and Leisure Studies and Co-Director of the Partnerships in Dementia Care Alliance at the University of Waterloo in Waterloo, Canada. She is committed to critical participatory action research and arts-based approaches as a means of promoting personal transformation, social justice, and social change in dementia and long-term care.

**Marija Geiger Zeman** is a sociologist at the Institute of Social Sciences Ivo Pilar in Zagreb. She is interested in gender issues, ageing studies, (popular) culture and qualitative methodology. Recently she became a lecturer at the Faculty of Textile Technology and the VERN University of Applied Sciences in Zagreb.

**Chris Gilleard** is a visiting research fellow in the Division of Psychiatry at UCL, London, UK. He is the co-author (with Paul Higgs) of a number of books to do with ageing and later life, including *Cultures of Ageing: Self, Citizen and the Body* (Pearson, 2000); *Contexts of Ageing: Class, Cohort and Community* (Polity, 2005) and *Ageing, Corporeality and Embodiment* (Anthem, 2013).

**Julia Gray** is a playwright, theatre director, physical theatre creator, and researcher, and is currently a post-doctoral fellow at Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada. Her work focuses on the intersection of arts, learning, health and social change. She recently edited 'ReView: an anthology of plays committed to social justice' (Sense Publishers) which includes 'Cracked: New Light on Dementia'.

**Jennifer Henke** is Assistant Professor at the University of Bremen where she received her PhD for the thesis *Unsex Me Here* (WVT 2014) on Shakespeare, gender, and film. She is currently working on her second book that deals with obstetrics in the literature and culture of the long eighteenth century. Her research interests include science and literature, the history of medicine, and visual culture.

**Paul Higgs** is Professor of the Sociology of Ageing, Division of Psychiatry, University College London. He is the co-author of a number of books addressing

the social cultural and political aspects of later life, including (with Ian Jones) *Medical Sociology and Old Age* (Routledge, 2009); (with Chris Gilleard) *Rethinking Old Age: Theorising the Fourth Age* (Palgrave Macmillan, 2015) and (with Martin Hyde) *Ageing and Globalisation* (Policy, 2016).

**Mirela Holy** is Professor of Ethnology and Comparative Literature. Following an activist and political career she works at the VERN University of Applied Sciences in Zagreb. She has published three books as well as many articles about relevant public issues (environment, human rights, women's rights, communication etc.).

**Christine Jonas-Simpson** is Associate Professor of Nursing at York University and is the Director of Academics and Philosophy at the Dotsa Bitove Wellness Academy, which is a relational arts-based academy for persons and families living with dementia. She is a relational arts-based researcher and teacher who has produced and directed several research-based short films and documentaries on living and transforming with loss.

**Pia Kontos** is a Senior Scientist at Toronto Rehabilitation Institute-University Health Network and Associate Professor in the Dalla Lana School of Public Health at the University of Toronto. She has published across multiple disciplines on embodiment, relationality, ethics, and dementia. She has also produced numerous research-based dramas to foster culture change in dementia care.

**Monique Lanoix** is Associate Professor of Philosophy at St. Paul University in the Centre for Research in Public Ethics and Governance where she teaches courses in feminist ethics, human rights and environmental ethics. Her research examines ancillary care and the manner in which it is structured and funded.

**Patricia Life** recently completed a PhD in English Literature at the University of Ottawa. Her research focuses on stories of the nursing home in Canadian literature and on the age ideologies that inform them.

**Gail J. Mitchell** is Professor of Nursing in the School of Nursing at York University. She is an arts-based researcher and teacher who has been involved in creating multiple research-based dramas. Dr. Mitchell has multiple publications and is one of a team of educators creating innovative teaching-learning technology informed by relational and complexity pedagogy.

**Aynsley Moorhouse** (MFA, MSW, RSW) is a Toronto-based Artist and Social Worker at the Alzheimer Society of Toronto. Aynsley has presented her work

and lectured in university classrooms, hospitals, academic conferences, arts festivals and on CBC Radio challenging assumptions about aging, specifically regarding memory loss and dementia. Her particular interest lies in how arts engagement can lead to personal growth and social change.

**Peter Simonsen** is Professor of European Literature at the University of Southern Denmark. He has published widely on British Romanticism and in more recent years he has researched contemporary Danish and English language fictions about old age, especially in relation to the welfare state.

**Betsy Struthers** is the author of nine books of poetry, three novels and a collection of short fictions. A past president of the League of Canadian Poets, she co-edited and contributed to an anthology of essays about teaching poetry. "Second Sitting" was previously published in the online journal *Sugar Mule* 33; it and the other poems here are included in Struthers' current work in progress, *First Snow on the Apple Trees*. She lives in Peterborough, Ontario.

**James Struthers** is Professor Emeritus in Canadian Studies at Trent University, and a member of the Trent Centre for Aging & Society. He is the author of two monographs on Canadian welfare state history and many chapters and articles on aging and Canadian social policy. He is currently a co-investigator in the multi-disciplinary project "Re-imagining Long-term Residential Care: an International Study of Promising Practices."

**Aritha van Herk** is Professor of Canadian Literature and Creative Writing at the University of Calgary. She has published five novels and seven works of criticism and non-fiction, as well as hundreds of essays and short stories. Her latest work is the prose-poetry collection, *Stampede and the Westness of West* (Frontenac House, 2016).

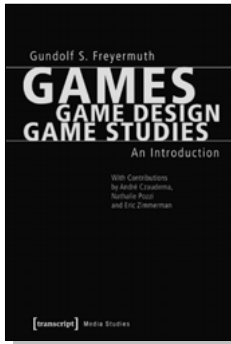
**Peter Whitehouse** is Professor of Neurology and former or current Professor of Psychiatry, Psychology, Cognitive Science, Neuroscience, Bioethics, History, Nursing and Organizational Behavior at Case Western Reserve University, Professor of Medicine at the University of Toronto, and President of Intergenerational Schools International. In 1986 he moved to Case Western Reserve University to develop the University Alzheimer Center. In 1999 he founded with his wife, Catherine, The Intergenerational School, a unique public multiage, community school ([www.tisonline.org](http://www.tisonline.org)). He is a geriatric neurologist, cognitive scientist, environmental ethicist, and photographer. He is active in visual arts, dance and music organizations globally.

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**Anne M. Wyatt-Brown** is Associate Professor Emeritus of Linguistics at the University of Florida, Gainesville. Her most recent publication consists of two essays in *The Big Move: Life Between the Turning Points* (Bloomington and Indianapolis, Indiana University Press, 2016), edited by Anne M. Wyatt-Brown, Ruth Ray Karpen, Helen Q. Kivnick, and Margaret Morganroth Gullette.

**Zdenko Zeman** is a sociologist and philosopher at the Institute of Social Sciences Ivo Pilar in Zagreb. He is author of two books and many articles, and also co-author of four books. He is interested in sociological and philosophical theories of (post)modernity and (post)modernization, aging studies and qualitative methodology.

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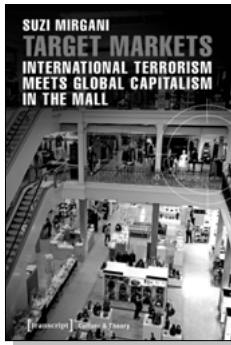
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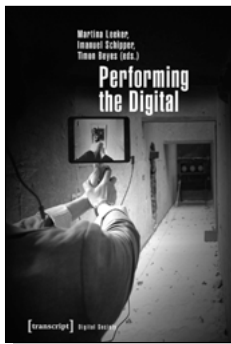
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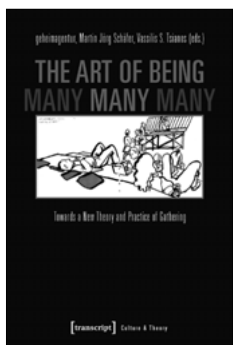
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